Family Psychoeducation Toolkit

Evidence-Based Practices: Shaping Mental Health Services Toward Recovery

This document is part of an evidence-based practice implementation resource kit developed through a contract (no. 280-00-8049) from the Substance Abuse and Mental Health Services Administration's (SAMHSA) Center for Mental Health Services (CMHS) and a grant from The Robert Wood Johnson Foundation (RWJF), and support from the West Family Foundation. These materials are in draft form for use in a pilot study.

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IMPLEMENTATION RESOURCE KIT USER'S GUIDE

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Foreword

The Substance Abuse and Mental Health Services Administrations (SAMHSA) Center for Mental Health Services (CMHS) is a proud sponsor of this implementation resource kit for Family Psychoeducation. As the federal agency responsible for promoting the quality, availability, and accessibility of services for people with mental illness, CMHS is responsible for identifying treatments for mental illness that work. The materials in this resource kit document the evidence for the effectiveness of Family Psychoeducation and provide detailed information to help communities to implement the practice in real world settings. During development of the implementation resource kit, we placed special emphasis on 1) strengthening the consensus-building process, 2) expanding the involvement of consumers and families, 3) including practical orientation to issues involving service organization and financing, and 4) insisting on paying careful attention to issues of ethnic and cultural sensitivity and overall cultural competence. We are well pleased with the result.

Many other organizations contributed to developing this implementation resource kit. This broad coalition of researchers, providers, administrators, policy makers, consumers and family members, gives the resource kit its strength and vitality. We are especially appreciative of the support provided by The Robert Wood Johnson Foundation that sponsored the early stages of the Project, when evidence-based Family Psychoeducation was identified as a practice ready for widespread implementation. We agreed. This evidence-based practice has been consistently shown to reduce relapse rates of people who have mental illnesses and live with their families. CMHS has found the role of family members to be vital for assuring quality care for many consumers. Family psychoeducation is a proven way to engage family members, to relieve family tensions regarding mental illness, and to improve outcomes for consumers.

This implementation resource kit reflects the current state-of-the-art concerning evidence-based Family Psychoeducation. It addresses both the key ingredients of the clinical model and many practical considerations essential for successful implementation. It also describes the need for each community to adapt the model to its particular needs and characteristics. Careful attention to unique community needs, coupled with fidelity to the key ingredients of the practice, equals successful implementation. The closer the kit user comes to following the implementation resource kit guidance, the more likely the practice will yield good results for consumers.

As mental health services research and evaluation progress, CMHS hopes to support the development of implementation resource kits for additional evidence-based practices, and to refine this and other previously-developed resource kits to take new evidence into account. Indeed, evaluation of planned pilot projects for implementing this resource kit and associated implementation strategies will tell us much about how to make improvements in future versions. We hope that this and other evidence-based practice implementation resource kits will be helpful to communities across the nation as they strive to provide the most effective services possible for persons suffering from mental illness.

Introduction

Welcome to the Family Psychoeducation implementation resource kit. It has been produced by the Implementing Evidence-Based Practices Project as part of an effort to promote treatment practices in community mental health service settings that are known to be effective in supporting the recovery of adults with severe mental illnesses. The goal: to improve the lives of consumers by increasing the availability of effective mental health services.

The Users Guide begins by providing general information about the Implementing Evidence-Based Practices Project, including the goals and values of the project. This is followed by descriptions of the materials contained in the resource kit and their proposed role in the implementation process. The basic structure of an implementation plan is outlined. Specific suggestions for implementing the practice of Family Psychoeducation are presented in the Implementation Tips documents. This guide also contains a list of annotated references on Family Psychoeducation and a special populations appendix which provides a review of the literature addressing the range of populations for which this practice has demonstrated efficacy or effectiveness.

If you have any questions or comments about these materials or the implementation process, please contact Kristine Knoll at the NH-Dartmouth Psychiatric Research (e-mail address: Kristine.M.Knoll@Dartmouth.EDU). We look forward to supporting your efforts to improve services to people with severe mental illness. Also, please share your experience in using these materials. Feedback from users will help refine and improve future versions of these implementation materials.

Background

What are "evidence-based practices"?

Evidence-based practices are services for people with severe mental illness (consumers) that have demonstrated positive outcomes in multiple research studies.

Over the past 15 years, researchers in mental health service systems have gathered extensive data to support the effectiveness of several psychosocial and pharmacological treatments. In 1998, the Robert Wood Johnson Foundation convened a consensus panel of researchers, clinicians, administrators, consumers, and family advocates to discuss the research and to determine which practices currently demonstrated a strong evidence base. This project is an offshoot of these efforts.

The six evidence-based practices:

Six practices were identified as currently demonstrating a strong evidence base:

- standardized pharmacological treatment
- illness management and recovery skills
- supported employment
- family psychoeducation
- assertive community treatment
- integrated dual disorders treatment (substance use and mental illness)

Other evidence-based practices for the treatment of persons with severe mental illnesses are being identified and will be promoted as the research evolves. This project is only a beginning attempt to establish models and procedures. This list of identified practices is not intended to be complete or exclusive. There should be many evidence-based practices in the future. Some promising practices being researched currently include peer support programming, supported housing, trauma services, and treatment for people with borderline personality disorder.

What is an implementation resource kit?

An implementation resource kit is a set of materials-written documents, videotapes, PowerPoint presentations, and a website-that support implementation of a particular treatment practice.

Specific materials in this resource kit have been developed for each of the key stakeholder groups involved in the implementation effort:

- consumers of mental health services
- family members and other supporters
- practitioners and clinical supervisors
- program leaders of mental health programs
- public mental health authorities

Research has shown that providing practice guidelines to practitioners alone does not change practice. Change is most likely to occur and be sustained if all the major stakeholders in the mental health system are engaged and involved in the process of change. Therefore the materials and guidelines in this implementation resource kit are geared toward five different stakeholder groups. The materials for each specific stakeholder group were either written by representatives of that group or in close collaboration with them.

The resource kit materials are also designed to address three stages of change:

- engaging and motivating for change (why do it)
- developing skills and supports to implement change (how to do it)
- sustaining the change (how to maintain and extend the gains)

What is an implementation package?

An implementation package is a set of implementation materials (the resource kit) combined with complementary training and consultation that support implementation of the evidence-based practice. The resource kit materials are designed to be most effective when used with consultative and training services. As part of the Implementing Evidence-Based Practices Project, EBP implementation centers are being established in various states across the country to provide consultation and training.

How was this implementation resource kit developed?

A team made up of multiple stakeholders developed each resource kit: researchers, clinicians, program managers and administrators, consumers, and family members. Documents oriented toward specific stakeholder groups were either written by the stakeholders or in close collaboration with them. A consensus panel, also comprised of multiple stakeholders, reviewed the materials developed for all of the six implementation resource kits to ensure consistency of presentation and attention to the various perspectives of the different constituencies.

For more information

For a more detailed discussion of the project and the implementation strategies, refer to the enclosed Psychiatric Services articles:

Drake RE, Goldman HH, Leff HS, et al: Implementing evidence-based practices in routine mental health service settings. Psychiatric Services 52:179-182, 2001.

Torrey WC, Drake RE, Dixon L, et al: Implementing evidence-based practices for persons with severe mental illnesses. Psychiatric Services 52:45-50, 2001.

Project Philosophy and Values

The project rests on two philosophical tenets:

First, mental health services for people with severe mental illnesses should have the goal of helping people to develop high-quality, satisfying functional lives. That is, services should aim not just at helping consumers stay out of the hospital and reducing or stabilizing symptoms, but also at helping them to pursue their own personal recovery process. People want services that help them to manage their illnesses and to move ahead with their lives.

Second, consumers and their families have a right to information about effective treatments, and in areas where evidence-based practices exist, consumers and family members have a right to access effective services.

Evidence-based practices are not intended to be exclusive, mandatory, or rigid. Rather, they imply self-knowledge, self-determination, choice, individualization, and recovery.

Defining recovery

There have been many efforts to define the recovery philosophy. The Consumer Advisory Panel for the Implementing Evidence-Based Practices Project drafted the following brief statement. The principles of recovery that informed the development of the implementation resource kit materials are:

- hope
- personal responsibility
- education
- self-advocacy
- support

The cessation of symptoms is not necessarily equal to recovery. Each person develops their own definition of recovery, which many view as a process rather than a destination. It is important to know what is meant by "support." While the support of others is a valuable element in recovery, it does not include solving problems for another person or giving advice.

Empowerment is another critical component to recovery. A person becomes dis-empowered when choices are made for them, even when well-meaning supporters do it. Disempowerment also occurs when assumptions or judgments are made concerning an individual and their choices.

Recovery is most easily achievable when a person and those around them recognize the individual as a whole and complete person regardless of symptoms. One of the most valuable things a person can do for someone with psychiatric symptoms is to listen.

For more information

Copeland, Mary Ellen. Wellness Recovery Action Plan. 1997. Peach Press.

Ralph, Ruth O. Review of Recovery Literature: A Synthesis of a Sample of Recovery Literature 2000. Report produced for NASMHPD/National Technical Assistance Center for State Mental Health Planning.

How to Use the Resource Kit Materials—An Implementation Plan

Effective implementation of evidence-based practices is best achieved by using the materials with a structured complementary consultative and training program. As part of this project, a number of evidence-based practices implementation centers have been established throughout the country.

A brief description of a basic implementation plan that includes these supports is provided below. See the Implementation Tips for Mental Health Programs Leaders and Implementation Tips for Public Mental Health Authorities for more detailed suggestions regarding the implementation of Family Psychoeducation.

Consensus building

Build support for change

- identify key stakeholders
- provide information to all stakeholders
- develop consensus regarding a vision for the practice at your agency
- convey a vision and a commitment to all stakeholders

Enthusiasm for the implementation of the evidence-based practice can be generated by communicating how the practice benefits consumers and family members.

Use implementation resource materials:

- Distribute information materials to the key stakeholder groups.
- Hold informational meetings with key stakeholder groups.
- Have opinion leaders within the different stakeholder groups co-host these meetings. Include a viewing of the introductory videotape.
- An introductory PowerPoint presentation can be used to structure the informational meeting.

Developing an implementation plan

An action plan

- identify an agency implementation leader
- establish an implementation steering team that includes representatives from all stakeholder groups
- secure a consultant from an EBP implementation institute
- develop an implementation plan

Responsibilities of the implementation leader and implementation steering team include identifying and utilizing personnel, resources, and processes (administrative support and system changes) needed to support the evidence-based practice; an assessment of training needs; and development of an implementation timeline.

Consultants from EBP implementation centers can work with public mental health authorities and program leaders to inform them about the practice, to evaluate an agency's or system's commitment to change, and to assess current realities of financial incentives, staffing, and structure.

By developing partnerships with community organizations including peer support programs, consumer and family advocacy groups, police, homeless shelters, food banks, department of vocational rehabilitation, and others depending on the specific practice, the implementation leader and the implementation steering team can most effectively develop support for the practice. These groups may contribute to the development of an implementation plan.

Use of implementation resource materials:

- Implementation Tips for Public Mental Health Authorities is designed for individuals at the municipal, county, or state mental health authority.
- Implementation Tips for Mental Health Program Leaders is designed to be shared with the individuals in an agency that make and carry out decisions about the local resources and processes. This includes people who have responsibility for program management, training, policy development, program standards, data management, and funding.

Enacting the implementation

Making it happen

- involve agency personnel at all levels to support the implementation
- host a "kick-off" training where all stakeholders receive information about the practice
- host a comprehensive skills training for agency personnel who will be providing the practice
- arrange opportunities to visit programs that have successfully implemented the practice
- work with an implementation center for off-site support for the practice
- review current agency outcome measures relative to the practice and modify outcome data to monitor the practice. Learn how to make use of outcome measures in clinical practice and supervision
- work with a consultant/trainer to learn how to use the fidelity scale to identify strengths and weaknesses in the implementation effort

Trainers can work with the agency to offer an initial or "kickoff" training for all stakeholders. The trainer can then provide comprehensive skills training for those personnel within the agency who will be providing the practice. The trainers may offer to visit the program at least one day per month for the first six months, then one day every other month for the next six months, for ongoing training, consultation, supervision as needed by the program. The trainer may also be available on a weekly basis for phone consultation.

Use of implementation resource materials:

- Many agencies find it useful for the implementation leader and agency staff to familiarize themselves with the structure and processes of the practice by visiting an existing program. Before a site visit, the implementation leader and clinical supervisor(s) should review:
- Information for Practitioners and Clinical Supervisors
- Information for Mental Health Program Leaders
- Implementation Tips for Mental Health Program Leaders
- Workbook for Practitioners and Clinical Supervisors
- Materials that support training and clinical supervision
- Workbook for Practitioners and Clinical Supervisors
- Practice demonstration videotapes
- PowerPoint training presentation (available from the West Institute)

Trainers may also serve as consultants to the administrators of the program. This includes demonstrating the usefulness of outcomes data as a clinical feedback tool.

Monitoring and evaluation

Sustaining change: How to maintain and extend the gains

- establish a mechanism for continuous feedback regarding how the practice is being provided in an agency
- publicize outcome improvements from the practice
- use fidelity scales to monitor the practice implementation

Monitoring and evaluation occur in several ways. First, the use of consultants to provide side-by-side, ongoing consultation during the first one to two years of the program is very helpful. Consultants who are experienced in the practice can recognize problems and recommend changes to address them.

Use of implementation resource materials:

It is useful for programs to become comfortable early on with the measures that will be used for monitoring and evaluating the delivery of the practice: outcome measures and the fidelity scale. The information collected can be used not only to identify areas that are problematic, but also to identify areas of excellence. Feedback from these measures may be used to promote and strengthen clinical and programmatic effectiveness.

A Word about Terminology

Terms used in the Implementation Resource Kit materials

The materials were developed by people from a variety of backgrounds and perspectives. During development, it became evident that many different terms are used to describe the key stakeholders. For the sake of clarity and consistency, in most instances common terms are used to identify these groups throughout the implementation resource kits. In some situations more precise, or alternative, terminology is used. For instance, in the Supported Employment implementation resource kit, the term 'employment specialist' is often used rather than "practitioner."

Consumers, clients, people who have experienced psychiatric symptoms

These terms refer to persons who are living with severe mental illness and who use professional mental health services-the consumers of mental health services. The term 'consumer' is most frequently employed in the resource kit materials. In the Integrated Dual Disorders Treatment workbook and in the outcome measures document, the term 'client' is used. The Illness Management and Recovery resource kit uses the term 'people who have experienced psychiatric symptoms'.

Family and other supporters

This terminology refers to families and other people who provide support to a consumer, and recognizes that many consumers have key supporters who are not family members.

Practitioners and clinical supervisors

The term practitioner refers to the people who deliver the evidence-based practice. This is used instead of clinician, case manager, nurse, psychiatrist, therapist, etc. except when referring to a specific kind of role (e.g., the employment specialist in supported employment, or the prescriber in medication management). The term clinical supervisor is used to distinguish between an administrative supervisor and the person supervising the clinical work of the practitioner.

Mental health program leaders

This term is used to describe the person at the mental health provider organization who is trying to put the practice into effect. This term is used instead of program supervisor, operations director, program manager, or program administrator. The term is used because it makes it clear that this person's job is to lead with the support of the agency's administration.

Public mental health authorities

This term is used to describe the people who determine the regulations and funding structures of the public mental health system. We recognize that evidence-based practices are also implemented and overseen in the private sector.

Readings and Other Resources on Family Psychoeducation

Essential Readings for Practitioners

The following four books are recommended for those wanting to master this approach. The first includes key elements of the Anderson and Falloon approach and should be read first. The Miklowitz, et al., book is essential for those working with consumers with bipolar disorder.

McFarlane, W.R., Multifamily Groups in the Treatment of Severe Psychiatric Disorders, New York, NY, Guilford, 2002.

Anderson, C., Hogarty, G., Reiss, D., Schizophrenia and the Family, New York, NY, Guilford Press, 1986.

Falloon, I., Boyd, J., McGill, C., Family Care of Schizophrenia, New York, NY, Guilford Press, 1984.

Miklowitz, D.J., Goldstein, M., Bipolar Disorder: A Family-focused Treatment Approach, New York, NY, Guilford Press, 1997.

Additional Resources for Practitioners

Amenson, C., Schizophrenia: A Family Education Curriculum, Pacific Clinics, 1998. Provides 150 slides with lecture notes for a class for families with a member with schizophrenia.

- Includes information about the illness, medication and psychosocial treatments and the role of the family in promoting recovery.

Amenson, C., Schizophrenia: Family Education Methods, Pacific Clinics, 1998.

- Companion handbook to Schizophrenia: A Family Education Curriculum provides methods for forming a class, optimizing the learning of families, and dealing with typical problems that arise in conducting family classes.

Mueser K, Glynn S, Behavioral Family Therapy for Psychiatric Disorders, Oakland, New Harbinger Publications, 1999.

Psychopharmacology

The Essential Guide to Psychiatric Drugs by J. Gorman, St. Martin's Press, 1995.

- Written for a sophisticated consumer, it is the most accessible source of information about psychotropic medications.
- Distills the Physician's Desk Reference into understandable language.
- Describes the individual "trees" (such as Prozac) in the forest of medicines.
- "The benzodiazepines: Are they really dangerous?" is a typical section heading.

Medicine and Mental Illness by M. Lickey and B. Gordon, Freeman, 1991.

- A scholarly yet readable work written for professionals, it is best at teaching the principles of diagnosis, neurophysiology and psychopharmacological treatment of mental illness.
- Describes the "forest" of psychopharmacology, why it is there and how it works.
- "The blockade of dopamine receptors and antipsychotic potency" is a typical section heading.
- Does not discuss the profiles of individual medications.

Cultural Competence

The Cross-Cultural Practice of Clinical Case Management in Mental Health edited by Peter Manoleas, Haworth Press, 1996.

- A collection of useful articles about the role of gender, ethnicity, and acculturation in treatment seeking and response.
- Provides guidelines for engaging and intervening with specific ethnic and diagnostic groups in varying treatment contexts.

Videotapes

Schizophrenia Explained by William R. McFarlane, M.D. Produced by, and order from, the author at Maine Medical Center, 22 Bramhall Street, Portland, ME 04102. (Phone 207-871-2091) mcfarw@mmc.org.

- Provides a full review in lay language of the psychobiology of schizophrenia, emphasizing the key concepts in family psychoeducation: stress reduction, optimal environments and interactions for recovery, and support for the family's ability to contribute to recovery in many ways.
- Often used in lieu of a psychiatrist during Family Education Workshops and for staffs of case management programs, community residences and employment programs to help them understand how to assist consumers with this disorder.

Exploring Schizophrenia by Christopher S. Amenson, Ph.D. Produced by the California Alliance for the Mentally Ill (Phone 916-567-0163).

- Uses everyday language to describe schizophrenia and give guidelines for coping with illness for persons and their families.
- Surviving and Thriving with a Mentally Ill Relative by Christopher Amenson, Ph.D., Third edition 1998.
- Eighteen hours of good "home video quality" videotapes cover schizophrenia, bipolar disorder, major depressive disorder, medication, psychosocial rehabilitation, relapse prevention, motivation, and family skills.
- Order from Paul Burk, 1352 Hidden Springs Lane, Glendora, CA 91740. (Phone 626-335-1307).

Critical Connections: A Schizophrenia Awareness Video, produced by the American Psychiatric Association, 1997.

- A 30 minute video, designed by the APA to help consumers and families cope with the disabling effects of schizophrenia.
- Provides a hopeful, reassuring message about new medications and psychosocial treatments that assist with recovery.

Exploring Bipolar Disorder by Jerome V. Vaccaro, M.D., 1996.

- One hour professional quality videotape describes the illness, recovery, and the role of the family. Persons with the illness contribute valuable insights.
- Produced by and ordered from the California Alliance for the Mentally Ill, 1111 Howe Avenue, Suite 475, Sacramento, CA 95825. Phone 916-567-0163.

Periodicals

Schizophrenia Bulletin

- Highly technical and difficult to read but it is the ultimate source for research findings.
- The fall 1995 issue summarizes "Treatment Outcomes Research".

Psychiatric Services

- Practical articles in all aspects of mental illness.
- Brief clinically relevant articles on medication and other treatments.
- The most useful periodical for clinical staff.

Psychosocial Rehabilitation

- Practical psychosocial rehabilitation articles.
- Easy to read and understand.

- Provides “how to” details. Contains good consumer written articles.

Other Resources

There are a number of excellent books written for persons with a mental illness and their families to help them understand and deal with these illnesses. Many of these are helpful for professionals directly and all are important resources to which to refer patients and families. (See Reading List for Families.) Many of the professional and family books are offered at a discount by The National Alliance on Mental Illness, 200 N. Glebe Road, Suite 1015, Arlington, VA 22203-3754. Phone: 703-524-7600.

Books on Mood Disorders (Bipolar and Unipolar Depression)

A Brilliant Madness: Living with Manic Depressive Illness by Patty Duke and Gloria Hochman, (Bantam, 1992)

- Combines personal experience with clinical information to describe manic depression in understandable terms and provide guidelines for coping with it.

Control Your Depression by Peter Lewinsohn, Ricardo Munoz, Mary Ann Youngren, and Antonette Zeiss, (Prentice Hall, Englewood Cliffs, New Jersey, 1979)

- Self-help book which assesses contributors to depression and includes activities, relaxation techniques, thinking, social skills, self-control, and specific ideas and exercises for each problem area.

The Depression Workbook by Mary Ellen Copeland, (Harbinger, 1992)

- Assists individuals in taking responsibility for wellness by using charts and techniques to track and control moods.
- The most complete and useful self help book for bipolar and unipolar depressions.

The Feeling Good Handbook by David Burns, (Penguin, New York, NY, 1989)

- Self-help book presents rationale for cognitive therapy for depression.
- Gives specific ideas and exercises to help change thought patterns associated with depression and other problems.

Lithium and Manic Depression: A Guide by John Bohn and James Jefferson

- A very helpful guide for people with manic depression and their families regarding lithium treatment.
- Order from Lithium Information Center, Department of Psychiatry, University of Wisconsin, 600 Highland Ave., Madison, WI 53792.

Our Special Mom and Our Special Dad by Tootsie Sobkiewicz, (Pittsburgh: Children of Mentally Ill Parents, 1994 and 1996)

- Two interactive storybooks that allow primary school age children to understand and identify with the problems associated with having a mentally ill parent.
- Can be well utilized by a relative or therapist in individual or group work.

Overcoming Depression, Third Edition by D. & J. Papolos, (Harper & Row, 1997)

- A comprehensive book written for persons suffering from manic depression and major depression, as well as their families.
- The best source of information about these disorders.
- Does not offer coping strategies.
- This book and The Depression Workbook are the best two to read.

An Unquiet Mind by Kay Redfield Jamison

- A compelling and emotional account of the author's awareness, denial, and acceptance of her bipolar disorder.
- Offers hope for recovery to anyone who reads it.

Books on Dual Diagnosis (Mental Illness and Substance Abuse)

Alcohol, Street Drugs, and Emotional Problems: What You Need to Know by B. Pepper and H. Ryglewicz

- Informative pamphlets, come in versions for the client, for the family and for professionals.
- Can be ordered from TIE Lines, 20 Squadron Blvd. Suite 400, New York, NY 10956.

Lives at Risk: Understanding and Treating Young People with Dual Disorders by B. Pepper and H. Rygelwicz

- Poignant description of the combination of schizophrenia, mood disorders, and/or personality disorders with substance abuse.
- Strong on empathy and understanding of the multiple problems.
- Provides little specific guidance.

Hazelden Publications. RW9 P.O. Box 176, Center City, MN 55012-0176 Phone 1-800-328-9000. Publishes a large number of pamphlets and self-help books on substance abuse and dual diagnoses.

Examples of titles include:

- Preventing Relapse Workbook .
- Taking Care of Yourself: When a family member has a dual diagnosis .
- Twelve Steps and Dual Disorders .
- Understanding Schizophrenia and Addiction .

Books about Children who have a Mental Illness

Children and Adolescents with Mental Illness: A Parents Guide by E. McElroy, (Woodbine House, 1988)

- Useful guide written by a psychologist who heads the NAMI Children's and Adolescent network.

Educational Rights of Children with Disorders: A Primer for Advocates by Center for Law and Education, (Cambridge 1991)
Neurobiological Disorders in Children and Adolescents by E. Peschel, R. Peschel and C. Howe, (Oxford Press, 1992)

- Biological mental illnesses among children are less common and less understood "family problems".
- Helps to define childhood neurobiological disorders and gives guidance for finding appropriate treatment.

Books on Special Topics

Planning for the Future and the Life Planning Workbook by L. Mark Russell and Arnold Grant, (American Publishing Company, 1995)

- This book and accompanying workbook are guides for parents seeking to provide for the future security and happiness of an adult child with a disability following the parents' deaths.

A Parent's Guide to Wills and Trusts by Don Silver, (Adams-Hall, 1992)

- Information on how to protect a disabled child's financial future, written by an attorney and NAMI member.

Schizophrenia and Genetic Risks by Irving Gottesman

- This pamphlet contains detailed information about this single topic. It may be ordered from NAMI.

A Street is Not a Home: Solving American's Homeless Dilemma by Robert Coates, (Prometheus, 1990)

- Analysis and guide to dealing with homelessness among persons suffering from mental illness.

Suicide Survivors: A Guide for Those Left Behind by Adina Wrobleski, (Afterwards, 1991)

- With an understanding attitude, explores and offers coping suggestions for the many issues that confront families who have had a member commit suicide.

Reading List for Families with a Member who has a Mental Illness
(Annotations by Christopher S. Amenson, Ph.D.)

Books which offer Guidance to Families

Coping with Schizophrenia: A Guide for Families by Kim Mueser and Susan Gingerich, (New Harbinger, 1994)

- Comprehensive guide to living with schizophrenia and the best source for practical advice on topics including medication, preventing relapse, communication, family rules, drug use, and planning for the future.
- Includes forms and worksheets for solving typical problems.

Schizophrenia: Straight Talk for Families and Friends by Maryellen Walsh, (Morrow & Co., 1985)

- This book is written by a parent who, as a professional writer, thoroughly researched the field.
- This book is emotional in ways that will touch you and deals with all the issues important to families of persons of schizophrenia.
- If you can read only one book, select this one if you want to feel understood; select Understanding Schizophrenia to access current research on causes and treatments; select Coping with Schizophrenia if you want concrete advice about coping with the illness.
- Surviving Schizophrenia: A Family Manual, Third Edition by E. Fuller Torrey, (Harper & Row, 1995)

Beloved by the Alliance for the Mentally Ill because it was the first book in 1983 to support and educate families.

- Contains one of the best descriptions of "The Inner World of Madness".
- Discusses the major topics in easy to read and very pro-family language.

Troubled Journey: Coming to Terms with the Mental Illness of a Sibling or Parent by Diane Marsh and Rex Dickens, (Tarcher/Putnam, 1997)

- The best book for siblings and adult children.
- Helps to recognize and resolve the impact of mental illness on childhood.
- Seeks to renew self-esteem and improve current family and other relationships.

Understanding Schizophrenia: A Guide to the New Research on Causes and Treatment by Richard Keefe and Philip Harvey, (The Free Press, 1994)

- The best description of research on schizophrenia as of 1994.
- It provides more depth and detail than Surviving Schizophrenia and is a little more difficult to read.
- A must for families that want to understand the science of schizophrenia.

How to Live with a Mentally Ill Person: A Handbook of Day-to-Day Strategies by Christine Adamec, (John Wiley and Sons, 1996)

- This comprehensive, easy-to-read book is written by a parent.
- It reviews methods for accepting the illness, dealing with life issues, developing coping strategies, negotiating the mental health system, and more.

Books describing the Experience of Schizophrenia

Anguished Voices: Siblings and Adult Children of Persons with Psychiatric Disabilities by Rex Dickens and Diane Marsh, (Center for Psychiatric Rehabilitation, 1994)

- Collection of 8 well-written articles which describe the impact of mental illness on siblings and children.
- A poignant statement of the issues across the life span that need to be addressed when a person grows up with mental illness in the family.

Crazy Quilt by Jocelyn Riley, (William Morrow, 1984)

- Fictional account of a 13-year-old girl whose mother has schizophrenia.
- Written for children and adolescents.
- Provides understanding for these forgotten individuals.

Is There No Place on Earth for Me? by Susan Sheehan, (Houghton-Mifflin, 1982)

- A very realistic depiction of the experience of a schizophrenic woman is interwoven with information about legal, funding, and treatment issues.
- Gives a good description of historical and political influences on the treatment of persons suffering from schizophrenia.
- Won the Pulitzer Prize.

Tell Me I'm Here: One Family's Experience with Schizophrenia by Ann Devesch, (Penquin, 1992)

- Written by a United Nations Media Peace Prize winner and founder of Schizophrenia Australia, this book describes her family's experience.

The Quiet Room by Lori Schiller, (1994)

- The life story of a person who had an almost full recovery from schizophrenia with clozapine.
- Great for its inspirational value.
- Only one in a thousand clients recover to this degree.

The Skipping Stone: Ripple Effects of Mental Illness on the Family by Mona Wasow, (Science and Behavior Books, 1995)

- Describes the impact of mental illness on each member of the family in a "Tower of Babel".

The Girl with the Crazy Brother by Betty Hyland, (Franklin Watts, 1986)

- Written for adolescents by an Alliance for the Mentally Ill member.

Website Resources

Schizophrenia
www.schizophrenia.com

Bipolar Disorder
www.mhsource.com/bipolar
www.bpkids.org

NAMI
www.nami.org
www.nami.org/helpline/peoplew.htm (well-known people with mental illnesses)

Government Sites
www.samhsa.gov/cmhs
www.nimh.nih.gov

Professional Organizations/Publications
Most valuable for schizophrenia information of high quality from peer-reviewed journals would be the American Psychiatric Association's site:
www.psych.org

Multi-specialty site cooperating with APA:
www.medem.com
www.rcpsych.ac.uk/info (Psychological approaches to psychosis)

Early Intervention with Psychosis
www.iepa.org.au (International Early Psychosis Association)

Antistigma
www.adscenter.org

Stress and Drug Abuse
www.nida.nih.gov/DrugPages/Stress.html

Special Populations Appendix

A review of the literature addressing the range of populations for which family psychoeducation has demonstrated efficacy or effectiveness, including factors such as age, race, ethnicity, gender, diagnosis, nationality, institutional setting, sexual orientation, and rural or urban location.

The most consistent finding from the family psychoeducation (FPE) literature has been the absence of specific client factors predicting better outcomes. Diagnosis may be the closest to a specific indicator, but that is primarily because there are fewer published studies of outcomes for diagnoses other than schizophrenia. Specifically, symptomatologies, age, gender, disability status, prior hospitalization, duration of illness and education have been examined and none have proven to be strong or consistent predictors. Family expressed emotion at baseline has proven to predict outcome within studies of treatment effects, as it has in studies without intervention (1, 2). However, Falloon showed that outcome was better predicted by coping skill improvements in treatment for family members (3).

At present, FPE has been shown to be most effective for individuals diagnosed with schizophrenia. There have been at least 20 controlled trials, involving nearly 5000 consumers and their families, and two are underway in Scandinavia that will involve nearly 1000 consumers and their families. Outcome has been remarkably consistent across all but two of the published clinical trials (4, 5). For that reason, schizophrenia is the principal diagnostic focus of this toolkit. Briefly described within the Workbook, modifications have been developed and tested for bipolar disorder (6, 7), depression (8), borderline personality disorder (9) and OCD (10). Multifamily group versions for these disorders have recently been described in Multifamily Groups in the Treatment of Severe Psychiatric Disorders (11).

Single-family versions have been tested and found to be effective for bipolar disorder, and studies are underway for the other disorders.

Within-study comparisons of relapse rates for different ethnic groups have led to at least one set of indications, in this case for multi- or single-family formats. One of the U.S. studies was a large, multisite effectiveness study conducted in state- or city-operated clinics and hospitals, in which multifamily groups had significantly lower (by about 1/3) relapse rates in five of the six sites (12). This study also identified a subgroup for which the single-family format was more effective—African-American families with low expressed emotion and patients with unusually good response to medication during the index hospitalization (13). First-episode cases, regardless of other characteristics or ethnicity, did substantially better in multifamily group than in single-family sessions, a counter-intuitive finding, but one that was significant (13).

Randomized controlled trials of family psychoeducation have been conducted in settings and other countries in which there were significant numbers of Caucasian, African-American, Asian and Latino subjects. Earlier studies have been conducted in London (14-16), Pittsburgh (2), New York City(17), New York State (12), Los Angeles(1, 18), Philadelphia (19), Atlanta (19), New Jersey (20), and China (21, 22) and others. Recent studies in Spain (23-25), China (26-29), Scandinavia (30), Japan (submitted) and the U.K. (31) have demonstrated the same robust effects as in prior studies in English-speaking and other countries. That these effects are additive to, but not substitutive for, antipsychotic medication was illustrated in a recent German study (32).

The one exception to generalized effectiveness was noted in a study by Telles and colleagues in Los Angeles, in a Spanish-speaking immigrant sample (5). There was a reversed effect for behavioral family management (using a single-family format) among those from a less acculturated subgroup and no effect for those from the more acculturated subgroup. It appeared that the Los Angeles sample's immigrant status may have negated the effects of family intervention. At present, a study is underway testing the efficacy of psychoeducational multifamily groups in Latino people. Though early indications are much more positive than in the prior single-family study, final conclusions need to await outcome analysis.

Although more replications are desirable, all the evidence to date suggests that the effectiveness of family psychoeducation compared to conventional individual therapy generalizes to nearly all major cultural populations: British-American and Australian, African-American, Spanish/Latino, Scandinavian/Northern European, Chinese and Japanese. On the other hand, anecdotally, we know that culture and language pose significant barriers to providing family psychoeducation in some populations and, in any case, require culturally sensitive adaptations and need to be further explored empirically.

Some client factors have not been systematically examined in the literature. For example, we know of no studies that have examined sexual orientation and how that might affect outcomes in family psychoeducation programs.

Community characteristics do not appear to impose a major barrier to implementing this approach. Family psychoeducation has been successfully implemented in both very urban and very rural settings, as well as in mid-sized cities and suburbs. Ironically, some of the most impressive outcomes have occurred among minority members of distressed and poverty-stricken urban populations (1, 12, 19). Many different states have implemented the model (33-35).

Nearly all of the controlled research on effectiveness has been conducted in outpatient clinics and community mental health centers, beginning treatment in several studies during an inpatient hospital stay. The multifamily group model was developed in a partial hospital in the South Bronx of New York City. The extent to which family psychoeducation can be successfully adapted to other types of provider agencies is not known. Ranz and colleagues developed an adaptation for application in community residences, with or without family participation, that appeared to alleviate stresses within the residences and improved outcomes, but a rigorous trial of this approach has not been completed (36).

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INFORMATION FOR CONSUMERS

Does your family

- understand your symptoms?
- know how to help you?
- understand what you need?
- understand your recovery process?
- know how to help you with recovery?
- have a good relationship with you?

Family Psychoeducation can help you and your family work together towards recovery.

Understanding Family Psychoeducation

When you have a mental illness, it can be hard on the whole family. Sometimes it may feel like your family doesn't understand what you're going through, or how to help you. Family psychoeducation is a way you can recover with your family's help. It is a way your family can learn what kind of help you would like from them.

Who is Family Psychoeducation for?

This program will help if you have a mental illness and other problems, especially when a stay in the hospital has been necessary. Family psychoeducation has been shown to be helpful for persons with:

- schizophrenia
- schizoaffective disorder
- bipolar illness
- major depression
- borderline personality disorder.

Who is included in Family Psychoeducation?

Anyone who is helping and/or supporting you in your recovery - parents, other relatives, close friends, neighbors. They do not have to live in your house or apartment.

How will Family Psychoeducation help?

You and your family learn ways to work together to support your recovery by solving problems that interfere with recovery. Your participation in this program may result in fewer symptoms, fewer relapses, and better relationships. The goal is to help you with recovery while getting more out of community life. You and your family work with practitioners to solve problems like...

- finding and keeping a job
- taking part in social activities
- family stress
- disagreements about medication
- lack of energy
- drugs and alcohol

What do other people have to say?

"It was only after I entered a multi-family group about four years ago that I came to terms with my illness . . .right off you could see that its organized to help the patient and the family find out what works for you as an individual. The thing that really helped me start to change is the problem solving [format]. You could see other people trying things and moving ahead that gave you hope to try things, too." -- *a consumer*

What changes will I see?

Studies show that when you and your family learn to solve problems related to your illness, your path to recovery will have:

- more involvement in family life and social activities
- better health and fewer medical problems for all family members
- better work opportunities
- fewer relapses
- less time in the hospital
- fewer symptoms
- less need for medication
- less depression, more energy and motivation

Plus...
Your family can help you reach your goals.

How does it work?

You become part of a team made up of you, your family and practitioners. Sometimes, families of other people with mental illness are involved, too. While working on your recovery, you learn the difference between the illness and who you are as a person.

Introductory sessions

You and your family meet with a practitioner, together or separately. You talk about what is going on, such as your hopes for the future, family problems, your symptoms, or medication.

Educational workshop

You and your family learn about your mental illness and ways you all can help with your recovery...especially by staying well.

Problem-solving groups

You and your family learn how to identify and deal with the problems that mental illness puts in the way of recovery and life. Sometimes there is more than one family in the group; then you share information and ideas for getting ahead. You meet once every other week, for as long as you find it helpful.

How do I start?

Tell your family, case manager, therapist, nurse or psychiatrist you are interested in this type of program.

INFORMACIÓN PARA LOS CONSUMIDORES

¿Su familia . . .

- comprende sus síntomas?
- sabe cómo ayudarle?
- comprende lo que usted necesita?
- comprende su proceso de recuperación?
- sabe cómo ayudarle en su recuperación?
- tiene una buena relación con usted?

La Psicoeducación de la Familia puede ayudarle a usted y a su familia a que trabajen juntos hacia la recuperación.

Comprendiendo la Psicoeducación de la Familia

Cuando uno tiene una enfermedad mental, puede que sea difícil para toda la familia. Algunas veces aparentemente su familia no comprende lo que usted está sufriendo, o como ayudarle. La psicoeducación de la familia es una de las maneras por medio de las cuales con la ayuda de su familia usted puede recuperarse. Es la manera en que su familia aprende que clase de ayuda usted desearía de parte de ellos.

¿Para Quién es la Psicoeducación de la Familia?

Este programa le ayudará si usted tiene una enfermedad mental y otras complicaciones, especialmente cuando una hospitalización ha sido necesaria. La psicoeducación ha demostrado que puede ser de ayuda para las personas con:

- esquizofrenia
- trastorno esquizoafectivo
- enfermedad bipolar
- depresión mayor
- trastorno límite de la personalidad

¿A quién se incluye en la Psicoeducación de la Familia?

Cualquier persona que le ayuda y/o le apoya en su recuperación - padres, otros parientes, amigos cercanos, vecinos. Ellos no tienen que vivir con usted en su casa o apartamento.

¿**Cómo puede ayudar la Psicoeducación de la Familia?**

Usted y su familia aprenden diferentes maneras de trabajar juntos para que le ayuden en su recuperación aprendiendo a resolver los problemas que interfieren con su recuperación. Su participación en este programa puede resultar en una reducción de síntomas, menos recaídas, y mejores relaciones familiares. La meta es ayudarle en la recuperación mientras pueda sacarle la mayor ventaja a la vida en la comunidad. Usted y su familia trabajan con profesionales para solucionar problemas como:

- encontrar y mantener un trabajo
- participando en actividades sociales
- el estrés de la familia
- desacuerdos sobre las medicinas
- falta de energía
- drogas y alcohol

¿Qué es lo que las otras personas tienen que decir?

“Fue solamente después que yo entré a un grupo de multi-familias hace unos cuatro años que pude aceptar mi enfermedad... de inmediato uno puede ver que el programa está organizado para ayudar al paciente, y la familia aprende lo que funciona para ti como un individuo. Lo que verdaderamente me ayudó a comenzar a cambiar es el (proceso) de

resolver problemas. Uno puede ver a otras personas haciendo esfuerzos y saliendo adelante y eso le da a uno esperanza de seguir luchando también." -- *un consumidor*

¿Qué cambios podré ver yo?

Los estudios demuestran que cuando usted y su familia aprenden a resolver problemas relacionados con su enfermedad, su camino hacia la recuperación tendrá:

- mas envolvimiento en la vida familiar y en actividades sociales
- mejor salud y menos problemas médicos para todos los miembros de la familia
- mejores oportunidades de trabajos
- menos recaídas
- menos hospitalizaciones
- reducción de síntomas
- menos necesidad de medicinas
- menos depresión, mas energía y motivación

Aun Mas...
Su familia le puede ayudar a alcanzar sus metas.

¿Cómo funciona esto?

Usted se convierte en un miembro de un equipo compuesto por usted, su familia y profesionales de la salud mental. Algunas veces, miembros de familias de otras personas con enfermedad mental se involucran también. Mientras que usted trabaja en su recuperación, usted aprende la diferencia entre la enfermedad y quien es usted como una persona.

Sesiones introductorias

Usted y su familia se reunen con un profesional de la salud mental, juntos o separados. Usted habla sobre lo que le está pasando, tales como sus esperanzas para el futuro, los problemas familiares, sus síntomas, o medicinas.

Talleres educacionales

Usted y su familia aprenden sobre su enfermedad mental y la manera como todos juntos pueden ayudar en su recuperación...especialmente el mantenerse sano.

Grupos de resolución de problemas

Usted y su familia aprenden a identificar y a enfrentarse a los problemas que la enfermedad mental presenta y como afecta su recuperación y su vida. Algunas veces hay mas de una familia en el grupo; entonces usted comparte información e ideas con ellos para salir adelante. Se reunen una vez cada dos semanas, por todo el tiempo que usted lo encuentre ventajoso.

¿Cómo empiezo?

Dígale a su familia, a la persona que maneja su caso, terapéuta, enfermera o psiquiátra que usted está interesado en esta clase de programa.

INFORMATION FOR FAMILIES AND OTHER SUPPORTERS

Would it help if your family

- understood more about symptoms of mental illness?
- knew how to help with a mental illness?
- could help better with recovery?
- had less stress overall?

Family Psychoeducation can help your family with these concerns.

Understanding Family Psychoeducation

When someone you care about has a serious mental illness, it can be hard on the whole family. You want to help your family member get better, but may not know how. Family psychoeducation is a way you can help your family member get better and make life less stressful for your whole family.

Do I have to be a family member?

No. You just have to be willing to be supportive of the person with mental illness. You do not have to live in the same house. Other relatives, close friends, and even neighbors can be very helpful.

How can this help my family?

- You learn about mental illness.
- You learn that other people have similar needs and experiences.
- You may have improved family relationships and general health.
- You learn new ways to deal with the common problems caused by the illness, problems that often create stress, confusion and disagreements, such as:
- taking medication
- finding and keeping a job
- taking part in social activities

How does it work?

You and your family meet as a single family with a practitioner or in a group with other families of people with mental illness. Groups are held every other week for several months. Studies have shown the best results occur when your family meets for at least nine months. Additional time promotes improved outcomes.

What is the format of family psychoeducation?

Introductory sessions

Family members meet with a practitioner, together or separately. The focus is to talk about what is going on, such as troubling symptoms, daily routine, lack of a job, etc. The family and practitioner start to develop a partnership during this time.

Educational workshop

For families in both single and multi-family psychoeducation, this is a key element. Families come together in a classroom session to learn the basics of mental illness, as well as what the family can do to work together towards recovery and stay well.

Problem-solving sessions

You meet every two weeks for the first months, then once a month for as long as you choose to meet. You may choose to meet as a single family or in a group. You learn to deal with the problems in a practical, step-by-step approach.

Who can benefit from family psychoeducation?

Families of people diagnosed with schizophrenia or schizoaffective disorder are most likely to benefit. Recently, psychoeducation has been shown to be helpful for people with bipolar disorder, major depression, obsessive compulsive disorder, and borderline personality disorder.

How does it help the consumer?

Over time, when individuals with serious mental illness and their families learn more about the illness and ways to reduce its effects, there can be many positive changes, such as:

- fewer relapses
- less time in the hospital
- a decreased sense of stigma
- a feeling of better control over life
- fewer symptoms
- fewer conflicts about medication
- less isolation
- more involvement in family life and social activities
- better job options
- less depression and anxiety

How do I start?

Tell the consumer, his/her case manager, or anyone on the treatment team that you are interested in family psychoeducation.

INFORMACIÓN PARA LAS FAMILIAS Y GRUPOS DE APOYO

¿Ayudaría si su familia . . .?

- Comprendiera más sobre los síntomas de la enfermedad mental?
- supiera como ayudarle con la enfermedad mental?
- pudiera ayudar mejor en la recuperación?
- tuviera menos estrés en general?

La Psicoeducación de la Familia puede ayudar a su familia con estas preocupaciones.

Comprendiendo la Psicoeducación de la Familia

Cuando una persona a quien queremos padece de una enfermedad mental seria, puede ser bien difícil para toda la familia. Usted quiere ayudar a ese miembro de su familia a que mejore, pero puede ser que no sepa como hacerlo. La psicoeducación de la familia es una manera de ayudar al miembro enfermo de su familia a que mejore y hacer que la vida sea menos estresante para toda su familia.

¿Tengo que ser un miembro de la familia?

No. Solo tiene que desear dar apoyo a la persona con la enfermedad mental. Usted no tiene que vivir en la misma casa. Otros parientes, amigos cercanos, y hasta vecinos pueden ser de mucha ayuda.

¿Cómo puede esto ayudar a mi familia?

- Aprende mas sobre la enfermedad mental.
- Aprende que otras personas tienen necesidades y experiencias semejantes.
- Mejora las relaciones de familia y la salud en general.
- Aprende nuevas formas para enfrentarse con los problemas comunes causados por la enfermedad, problemas que frecuentemente crean estrés, confusión y desacuerdos, tales como:
    - el tomar la medicina
    - consiguiendo y manteniendo un trabajo
    - tomando parte en actividades sociales

¿Cómo funciona?

Usted y su familia se reunen con un profesional de la salud mental o con otras familias de personas con una enfermedad mental. Los grupos se reunen durante cada dos semanas por varios meses. Las investigaciones han demostrado que los mejores resultados ocurren cuando su familia se reune por lo menos nueve meses. El tiempo adicional promueve los mejores resultados.

¿Cuál es la manera en que se conduce la psicoeducacion de la familia?

Sesiones introductorias

Los miembros de la familia se reunen con un profesional de la salud mental, juntos o separados. El enfoque es hablar sobre lo que está pasando, por ejemplo, los síntomas problemáticos, la rutina diaria, la falta de trabajo, etc. La familia y el profesional comienzan a desarollar una relación profesional durante este tiempo.

Taller educacional

Para las familias que están en la psicoeducación, bien sea ellos solos o en una forma de multi-familias, este es el elemento clave. Las familias se reunen y reciben una clase para aprender los puntos básicos sobre la enfermedad mental, y también lo que la familia puede hacer para trabajar juntos hacia la recuperación y para mantenerse sanos.

Sesiones de resolución de problemas

Usted se reune cada dos semanas durante el primer mes, y después una vez al mes por el tiempo que usted desee hacerlo. Usted puede escoger reunirse como una sola familia solamente o en un grupo. Usted aprende a enfrentarse paso a paso con los problemas de una manera práctica.

¿Cómo ayuda al consumidor?

Después de un tiempo, cuando los individuos con una enfermedad mental seria y sus familias aprenden mas sobre la enfermedad y las maneras para reducir sus efectos, puede haber muchos cambios positivos, tales como:

- menos recaídas
- menos hospitalizaciones
- un sentimiento de reducción del estigma
- un sentimiento de mejor control sobre la vida
- menos síntomas
- menos conflictos en relación con los medicamentos
- menos aislamiento
- mas envolvimiento en la vida familiar y actividades sociales
- mejor opciones de trabajos
- menos depresión y ansiedad.

¿Cómo empiezo?

Dígale al consumidor, a la persona que maneja su caso, o a cualquier persona en su equipo de tratamiento, que usted está interesado(a) en la psicoeducación de la familia.

INFORMATION FOR PRACTITIONERS AND CLINICAL SUPERVISORS

Who benefits from Family Psychoeducation?

People diagnosed with schizophrenia or schizoaffective disorder and their families have shown the most benefit from family psychoeducation. There simply needs to be an interest in improving family relationships while learning what to do about the symptoms of mental illness. Recently, family psychoeducation has been shown to be helpful for people with bipolar disorder, major depression, obsessive compulsive disorder, and borderline personality disorder. Family is defined as anyone committed to the care and support of the person with mental illness and does not have to be a blood relative. In fact, consumers often ask a close friend or neighbor to be their support person in the group.

What is family psychoeducation?

It is an elaboration of models developed by Carol Anderson, Ian Falloon, Michael Goldstein and William McFarlane. For multi-family groups, practitioners invite 5 to 6 consumers and their families to participate in a psychoeducation group for at least six months. Additional meeting time promotes improved outcomes. Meetings are held every other week. The format is structured and pragmatic to assist people with developing skills for handling problems posed by mental illness. Over time, practitioners, family members,
and consumers form a partnership as they work toward recovery. Consumers and their supporters may decide to meet as a single family rather than in the multi-family group format.

Family psychoeducation involves:

- joining (developing an alliance)
- on-going education about the illness
- problem-solving
- creating social supports
- developing coping skills

Why should practitioners consider family psychoeducation?

Family psychoeducation builds on the family's important role in the recovery process of people with mental illness. This approach is for practitioners who want to see markedly better outcomes for consumers by involving their families or support people. Family psychoeducation can be used in a single or multi-family format. It does not replace medication.

What are the benefits of family psychoeducation?

- improved clinical outcomes, community functioning, and satisfaction for consumers
- diminished interpersonal strain and stress within families
- higher rates of employment and recovery
- reduced need for crisis intervention and hospitalization over time
- improved cost-benefit ratio

The American Psychiatric Association cites family psychoeducation, used in conjunction with medication, as one of the most effective ways to help in the recovery process for schizophrenia. Research has shown that thereis a significant reduction in relapse rates and unemployment when family intervention, multi-family groups, and medication are used concurrently.

Who provides family psychoeducation?

A family psychoeducation practitioner can be a social worker, nurse, doctor, occupational therapist, employment specialist, or case manager.

What skills will I gain?

Many practitioners find their work with families helps them to develop their own knowledge and professional skills. They mention:

- improved understanding of the effect of illness on family relationships
- improved understanding of consumer and family perspectives
- improved ability to shift perspectives from leader to partner
- more effective family, cognitive, and behavioral therapy skills

Why work with families?

According to the World Fellowship for Schizophrenia and Allied Disorders, there are multiple reasons:

- to achieve the best possible outcome for the consumer through collaborative treatment and recovery
- to ease suffering among family members by supporting their efforts to foster their loved one's recovery
- to listen to families and treat them as equal partners
- to provide relevant information for consumers and families at appropriate times
- to provide training for the family in structured problem-solving techniques
- to pay attention to the social, as well as the clinical needs, of the consumer and family
- to explore family members' expectations and assess a family's strengths and difficulties
- to encourage clear communication among family members

Practitioner experience:

"The patient is much better—more active, more aware of his illness, and exerts more control over recognizing [early warning signs] and getting help early on."
L.B. (multi-family therapist)

"The family is … more knowledgeable and more hopeful."
R.L. (single family therapist)

INFORMATION FOR MENTAL HEALTH PROGRAM LEADERS

What is family psychoeducation?

Family psychoeducation is a method of working in partnership with families to impart current information about the illness and to help them develop coping skills for handling problems posed by mental illness in one member of the family. The goal is that practitioner, consumer, and family work together to support recovery. It respects and incorporates their individual, family, and cultural realities and perspectives. It almost always fosters hope in place of desperation and demoralization.

Psychoeducation can be used in a single family or multi-family group format, depending on the consumers and family's wishes, as well as empirical indications. Single family and multi-family group versions will have different outcomes over the long term, but there are similar components. The approach has several phases, each with a specific format:

Introductory sessions

Family members meet with a practitioner, together or separately, and begin to form a partnership. These sessions explore warning signs of illness, the familys reactions to symptoms and behaviors, feelings of loss and grief, and goals for the future.

Educational workshop

Families come together in a classroom format for at least four hours to learn the most current information about the psychobiology of the illness. They learn important information about normal reactions, managing stress, safety measures. Families choosing single family psychoeducation may also wish to attend this session.

Problem-solving sessions

Consumers and families meet every two weeks for the first few months in a single or multi-family format while learning to deal with problems in a pragmatic, structured way. The best results occur when the work proceeds for at least nine months. Additional time of up to two years promotes improved outcomes.

Why should mental health program leaders consider family psychoeducation?

Increasingly, mental health facilities are feeling pressure to meet the demands of service and productivity. Mental health program leaders find they need to direct services that will satisfy these demands without sacrificing the quality of care being offered. At the same time, program leaders are concerned about practitioners level of satisfaction.

The American Psychiatric Association and the Agency for Health Care Policy and Research cite family psychoeducation as one of the most effective ways to manage schizophrenia. Research has shown that there is a significant reduction in relapse rates (by at least 50% of previous rates) when family intervention, multi-family groups, and medication are used concurrently. Recent studies show promising results for bipolar disorder, major depression, and other severe mental illnesses.

What is the benefit of psychoeducation for practitioners?

Research has shown that psychoeducation provides practitioners with an opportunity to:

- Promote improved clinical outcomes, satisfaction, and higher rates of recovery amongst their clients
- Feel more supported in their efforts to manage the effects of illness
- Build relationships with families
- Experience improved cost-benefit ratios

In fact, many practitioners find that their work with families helps them develop their own professional skills. They describe an improved understanding of the effect of illness on family relations and an improved ability to shift their own perspectives from practitioner to partner.

Who is the target population?

The greatest amount of research has shown benefits for people with schizophrenic disorders and their families. Further, people who participate in family psychoeducation at an early stage of their illness have especially promising outcomes in terms of symptoms and employment. Increasing evidence shows that new versions for mood disorders, OCD, and borderline personality disorder are effective, as well for consumers who lack family support altogether. Thus, the population with the greatest benefit will be those with the most severe psychiatric disorders.

Family refers to anyone who cares about the consumer. It does not have to be a relative or a person sharing the same living space.

What can I do to implement family psychoeducation?

Mental health systems that have some psychosocial or psychotherapy services, can largely reallocate services toward family psychoeducation. If multi-family groups are established, total service efforts will actually decrease by the end of the first year. A recent cost-effectiveness study shows that the extra effort will be more than recouped in saved crisis/intensive treatment efforts and costs. Special arrangements may be needed to provide access to families from some cultural groups. It is very useful to consult with and involve the local or state chapter of NAMI.

This approach is designed to largely replace individual meetings with consumers. The most cost-effective approach is to simply include the family in most ongoing sessions, whether in single or multi-family group format. Most licensed mental health practitioners can learn to work within this model quite effectively. That includes social workers, psychiatric nurses, psychiatrists, psychologists, occupational therapists, and case managers. The usual steps toward establishing services include an agency-wide orientation and program consultation, intensive clinical training, and about one year of group supervision.

INFORMATION FOR PUBLIC MENTAL HEALTH AUTHORITIES

To help shape public mental health service delivery systems, public mental health authorities need current and accurate information about the goals and challenges of treating and providing services for people with severe mental illness. There is a growing body of research, known as evidence-based practices (EBP), which are principles and practices demonstrating the most effective services for people with severe mental illness. Family psychoeducation is one of those evidence- based practices.

What is family psychoeducation?

Family psychoeducation is a method of working in partnership with families to help them develop increasingly sophisticated and beneficial coping skills for handling problems posed by mental illness in their family and skills for supporting the recovery of their loved one. It respects and incorporates their individual, family, and cultural realities and perspectives. It almost always engenders hope in place of desperation and demoralization. Families of people diagnosed with the more severe forms of mental illness benefit the most from this treatment approach.

Family psychoeducation involves:

Joining with consumers and their families.

The practitioner establishes a respectful, trusting, and helpful relationship with family members, incorporating cultural perspectives on the meaning of mental illness and its treatment.

Education about the illness and useful coping skills.

The practitioner helps family members better understand their loved ones illness and what they can do about it.

Problem-solving strategies for difficulties caused by illness.

The practitioner works with the family to identify strategies for handling difficult situations, making use of effective behavioral, cognitive, and communication techniques.

Creating an optimal environment for recovery from mental illness.

The practitioner works with the family to establish a strengths-based environment where all members are respectful of one another.

Creating social and support groups.

The practitioner often carries out the treatment in multi-family groups. Families establish connections with others who have similar experiences and gain a broader social network. The other families in the psychoeducational workshop and ongoing multi-family groups support each other. Participation in local family support groups (National Alliance for the Mentally Ill) is also recommended.

Families of people diagnosed with schizophrenia or schizoaffective disorder benefit from this treatment approach. Many younger consumers being treated in outpatient clinics and those consumers who are unemployed will benefit as well by finding and keeping a job. This

approach also has applications for bipolar illness, major depression, or borderline personality disorder. It has been combined with assertive community treatment and supported employment to great advantage, clinically and vocationally.

What does the evidence say?

Extensive research demonstrates that implementing family psychoeducation in routine mental health settings dramatically improves the lives of people with severe mental illness. For consumers whose families participate, relapse rates and rehospitalizations decrease significantly within the first year following hospitalization when compared to groups who only use medication, with or without individual therapy. In several studies, relapse and rehospitalizations decreased in frequency by 50% or more. Family psychoeducation programs have provided the psychosocial supports consumers need to extend recovery, re-enter the work force, and develop social skills. Families report a decrease in feeling confused, stressed, and isolated. Recent studies have shown employment rate gains of two to four times baseline levels, especially when combined with supported employment, another EBP. Medical care costs for family members are reduced as well. Combined effects over several years lead to about 50% of consumers achieving five years without relapse, a very strong base for going on to recovery.

Family psychoeducation has proven to be markedly effective in reducing the cost of caring for people with severe mental illness. While the implementation of family psychoeducation may involve some up-front costs, studies consistently indicate a very low cost-benefit ratio, especially in savings from reduced hospital admissions, reduction in hospital days, and in crisis intervention contacts.

To help public mental health authorities implement family psychoeducation services into the system of care, resource kits have been developed to help agency administrators and mental health program leaders implement this approach for consumers and their families.

Why provide family psychoeducation?

- To achieve the best possible outcome for the individual with mental illness through an inclusive and collaborative care model.
- To reduce confusion and stress among family members, by informing and supporting their efforts to support the recovery of their loved one.
- To coordinate all elements of treatment and supportive services to ensure that everyone is working toward the same goals in a collaborative relationship.
- To listen to families and treat them as equal partners.
- To explore family members' expectations and assess a family's strengths and limitations in supporting recovery.
- To help resolve family conflict through sensitive response to emotional distress.
- To address feelings of loss among family members and consumers.
- To provide relevant information for consumers and families about mental illness and treatments that support recovery.
- To provide training for the family in structured problem-solving techniques.
- To encourage the family to expand their social support networks.
- To be flexible in meeting the needs of the family.

What is the role of families?

- Family is defined as anyone committed to the care and support of the person with mental illness, regardless of whether they are related or live in the same household.
- Families help create an optimal home and social environment for the individual with mental illness, as a key aspect of recovery. With consumers consent, families participate in the treatment teams decision-making processes about the individuals case, living situation, and recovery while being guided by the individual consumers wishes and perspective.

Are there cost savings with family psychoeducation?

Implementing a family psychoeducation program has initial costs related to training and organizational operations and procedures. In experimental studies the cost-benefit ratios of family psychoeducation are impressive. In a statewide study in New York, for every $1 in costs for FPE in multi-family groups, there was a $34 savings in hospital costs during the second year of treatment. In a typical hospital in Maine, there was an average net savings of $4,300 per consumer per year over two years. The minimum reduction in hospitalizations has been about 50%, with some studies achieving up to 75% reductions over time. There is, however, variability in the costs and cost savings by different authorities in different states.

Non-fiscal savings are achieved as complaints from families about services decrease and family support for the agency and the PMHA grows. In many communities this has translated into political support for funding for expanded and improved services.

How can family psychoeducation be funded?

Funding mechanisms may vary from agency to agency and state to state. For the most part, funds are used from the state Division of Mental Health and Medicaid. State leaders from the agencies work out a mechanism on how to pool monies that can be used to reimburse the services of family psychoeducation programs. In some cases Medicaid rules and codes have been rewritten to allow reimbursement for family psychoeducation. One state has adopted a case-rate approach, which fits well with implementation and promotes use of the modality. In this instance, the provider agency is reimbursed on a monthly basis for each consumer to cover bundled direct and indirect costs.

What training materials are available regarding family psychoeducation?

An implementation resource kit for family psychoeducation has been developed. Training components include: information sheets, introductory and training videos, workbooks, outcome and fidelity measures, and website supports. The materials have been developed for the major stakeholders, including consumers, families and supporters, practitioners and clinical supervisors, mental health program leaders, and public mental health authorities.

Family psychoeducation training is available from selected training institutes. Implementation should include, but is not limited to:

- Orientation programs for building understanding and consensus about family psychoeducation.
- Introduction to using the materials and learning the program philosophy and interventions.

- Clinical training workshops for practitioners interested and willing to adopt the practice.
- Supervision, conducted most commonly in groups, via live meetings, teleconferencing, phone, videotaping, or web groups.
- Initial and as-needed consultation to mental health program leaders and funding sources for problem solving.
- How will agencies know if they have a successful program?

How successful a family psychoeducation program is in improving outcomes depends, in part, on how closely the program follows the recommended practice. Programs that only partially adopt the practice or that allowed it to drift back into old ways of providing services may not produce the beneficial outcomes associated with family psychoeducation. A program fidelity scale has been developed that measures adherence to the family psychoeducation model. According to studies, programs that score high on this fidelity scale have better outcomes.

What is the role of the public mental health authority?

There are a variety of roles to play to turn a vision into reality.

- Articulate the vision. For example, family psychoeducation programs will be a core component of mental health services in our state.
- Disseminate the information about family psychoeducation to major stakeholders.
- Gain the interest and support of CEOs and clinical directors of outpatient and community mental health organizations.
- Promote the implementation of family psychoeducation through performance outcomes and financial incentives.
- Persuade clinical leaders and program executives of the need to institute services based on valuebetter outcomes at reduced overall cost and improvement in lives.
- Work with and develop partnerships with mental health centers, trade associations, and consumer and family advocacy groups to help adopt this approach.
- Provide financial and political support, including helping to resolve financial and organizational barriers.
- Arrange for and support financially ongoing training and staff development.
- Arrange for practitioners from the cultural groups represented in the catchment area, as well as interpreters as needed.
- Measure results and provide feedback to those who practice the approach.

IMPLEMENTATION TIPS FOR MENTAL HEALTH PROGRAM LEADERS

The Evidenced-Based Practices Project presents public mental health authorities with a unique opportunity to improve clinical services for adults with severe mental illness. Service system research has evolved to a point where it can identify a cluster of practices that demonstrate a consistent, positive impact on the lives of people who have experienced psychiatric symptoms.

Purpose

This document is designed to help you, as a mental health program leader, understand the contents of the family psychoeducation (FPE) resource kit; and to provide useful strategies for implementing a family psychoeducation program in routine clinical practice. This document draws upon the experiences of other mental health program leaders who have successfully implemented FPE programs, including multi-family psychoeducational groups, in their organizations.

What is family psychoeducation?

Family psychoeducation is a specific method of working in partnership with consumers and families in a long-term treatment model to help them develop increasingly sophisticated coping skills for handling problems posed by mental illness. The goal is that practitioner, consumer, and family work together to support recovery. Common issues are:

- participation in outpatient programs
- understanding prescribed medication
- drug or alcohol abuse
- symptoms that affect the consumer

Family psychoeducation respects and incorporates individual, family, and cultural perspectives. It engenders hope in place of desperation and demoralization.

Psychoeducation can be used in a single family or multi-family group format, depending on the consumers and family's wishes, as well as empirical indications. Single family and multi-family group versions will have different outcomes in the long term, but there are similar components. The approach has several phases, each having a specific format:

Joining with consumers and their families.

The practitioner establishes a rapport with family members and the consumer, which continues throughout their involvement in treatment. For many practitioners, this requires a shift in traditional roles.

Education about the illness and coping skills.

The practitioner helps families understand that their loved one suffers from a bona fide illness. This relieves families of their guilt and anxiety, so they are able to make major contributions toward recovery.

Problem-solving for difficulties caused by illness and circumstances created by the illness.

Problems are anything that interferes with treatment and recovery, as well as illness and symptom management.

Creating an optimal social environment for recovery from mental illness.

Multi-family groups promote coping skills and ongoing social contact. The family is supported by other families at the educational workshop and ongoing sessions. Families establish connections with others who have similar experiences and in turn gain a broader social network.

What does the evidence say?

Research has shown that, for consumers whose families participate in family psychoeducation programs, relapse rates and rehospitalizations decrease significantly within the first year following hospitalization when compared to groups who use medication, with or without individual psychotherapy. In several studies, relapse decreased in frequency by 50% or more. Especially when carried out in multi-family groups, this approach has provided the psychosocial support consumers need to extend recovery, re-enter the work force, and develop social skills, while their families report a decrease in feeling stressed and isolated. Recent studies have shown employment rate gains of 2 to 4 times baseline levels, especially when combined with supported employment services.

Why work with families?

- To achieve the best possible outcome for the individual with mental illness through collaborative treatment and rehabilitation
- To ease suffering among family members by supporting their efforts to foster their loved one's recovery
- To coordinate all elements of treatment and rehabilitation to ensure that everyone is working toward the same goals in a collaborative, supportive relationship
- To pay attention to the social, as well as the clinical needs of the consumer
- To listen to families and treat them as equal partners
- To explore family members expectations and assess a family's strengths and difficulties
- To help resolve family conflict through sensitive response to emotional distress
- To address feelings of loss
- To provide relevant information for consumers and families at appropriate times
- To encourage clear communication among family members
- To provide training for the family in structured problem-solving techniques
- To encourage the family to expand their social support networks
- To be flexible in meeting the needs of the family

Contents of the implementation resource kit

This resource kit includes information that helps the provider effectively lead the family psychoeducation group. Several tools are included, such as information sheets for consumers, families and practitioners, a workbook for learning the basic elements of the approach, fidelity, implementation process and outcome measures, and material for public mental health authorities. These are all intended to support providing services in a way that achieves the same kinds of remarkably improved outcomes that have been repeatedly demonstrated in prior outcome research studies.

Making it happen building momentum for the implementation of a family psychoeducation program

There is likely to be some apprehension among the organizations personnel about the new programs clinical value, its potential for increased workload for the staff, the need for training that the organization cannot afford, or changes to administrative procedures.
The following tips should alleviate some of these concerns and help the mental health program leader be successful:

Make one person responsible

Implementation of a family psychoeducation program has the greatest chance of success when a sole individual is responsible for leading the change. Success is more likely when that person is the clinical leader for the organization and when the senior administrators are aware and support the programmatic change. In particular, the agency's on-line staff must understand the conceptual framework of the program, be trained in its methodology, see its clinical value, and buy into their new role in the program. In many clinical settings, the leader will need to overcome barriers to implementation. The leader may need to advocate for funding, rally support of the executive director and other key leaders, or bring in consultants/trainers when needed.

Identify and deal with the possible barriers to implementation

When people are made aware of anticipated barriers, they seem to become more energized to overcome those barriers. When these concerns are addressed directly by the leadership they usually dissipate without much cost of time or money. Some of the commonly voiced concerns about family psychoeducation are:

- *There will be an increase in workload.* Studies have shown that over the first year the total workload for a given group of consumers will either be the same as or less than for standard individual therapy and/or case management.
- *Staff has no experience working with families of consumers.* Nearly every practitioner who has adopted this approach and followed the suggested methods has succeeded in achieving the same results as in clinical trials.
- *Consumers do not want their families involved with their treatment.* There are suggested methods for involving consumers in making decisions about including family members in treatment. Once they understand what is involved and how they will benefit, it is extremely rare that a consumer will not give consent and participate.
- *There is no time to learn a new treatment model, regardless of what the research outcomes indicate.* The first implementation will require extra time and effort, but it will be compensated by fewer crises, improved outcomes, and a much greater sense of accomplishment and gratification in ones work.
- It is difficult to find a colleague to co-lead groups. It is much more important to include families in the ongoing clinical and recovery work, so start on a single-family basis with a small number of cases and allow colleagues to see the results.
- Agency administration will not reduce or rearrange caseloads of staff. It will be the job of the program leader to allow for 34 months of reduced case load or relief from intake to set up family psychoeducational services, especially in a multi-family group. It will balance out quickly in improved clinical efficiency.
- It costs too much. The organizations leadership will need to ensure that reimbursement covers the slightly greater initial costs, if the program is to be maintained and achieve its potential cost savings.

- We have to change the procedures already in place. Yes, a few procedures will need to change, but they are minimal compared to the changes required for assertive community treatment or supported employment (other EBPs). Set up methods for determining which consumers have family available and join with families as soon as possible during an acute episode.

Provide meaningful reasons and incentives

Other key decision-makers in the programagency CEOs, financial directors, and medical directors—need incentives. They need to understand the cost-benefit ratios to buy into the suggested program change and to support the rest of the process.

Bring in outside speakers to inform and inspire the staff

Engaging a guest speaker who is a well-known expert in the field and a fellow practitioner can advance the credibility of your program. Consumers and their families can also testify about their experiences with family psychoeducation. This is especially effective if their agency is similar to yours.

Connect colleagues

Connecting family practitioners with colleagues who have similar roles in established programs is useful. Case managers tend to listen to other case managers, psychiatrists to psychiatrists.

Frame the adoption of FPE in positive terms

When discussing family psychoeducation with your agency use examples from practitioners who discover how their work suddenly seems more interesting, how they develop a more positive relationship with consumers and families, and how their work load (especially crisis intervention) decreases over time.

Educate practitioners about the research

Include studies and clinical experience that show good results in a variety of cultural groups (such as African-American, Chinese, Southeast Asians, Latino-Americans and others), socioeconomic populations, and geographic settings.

Use a consumer-centered management approach

(See appendix and the Illness Management and Recovery resource kit for more information.) This approach lets practitioners and clinical supervisors measure progress and success by consumer outcomes, rather than by process measures, such as hours of therapy or time in day treatment programs.

Making the change to a family psychoeducation program

Your goal in implementing the new program is to redesign the process of care so that it is easy for practitioners to completely commit to the family psychoeducation model. As a mental health program leader, you need to understand some of the family psychoeducation activities and procedures so that you can support the efforts of your staff.

Meet with families

- Initially, consumers and their families meet with a practitioner at least three separate times to review illness history, warning signs, coping strategies, concerns, and goals for themselves in the program. This is the stage in which rapport and trust are established, as well as the beginning of family education.
- Five to seven consumers and their families participate in one multi-family group. All of these sessions should be reimbursable by insurance. The sessions may last up to two years and often continue longer by request of consumers and their families.
- Five to seven families come together to learn specifics of the illness in a daylong workshop before the first multi-family group or single-family session.
- Some families prefer, and benefit from, continuing in a single-family format.

The program requires co-facilitators

Some agencies report that having three facilitators for multi-family groups is helpful, since it allows staff to rotate through the group, as well as take turns observing one another's techniques. Single-family work is usually done by one practitioner only.

FPE and multi-family groups have a pragmatic, structured, problem-solving format

Experience with group process is not a prerequisite for successful co-facilitation. Staffs interested in learning a new group model often embrace the multi-family group.

Initially co-facilitators take a reduced caseload

Or do not take on new cases. For the first three to four months of family psychoeducation, staff should have no new cases so that the program can get off to a good start. In some instances caseloads are reorganized so that the family psychoeducation cases, especially in multi-family groups, are comprised of participants from more than one clinical caseload, which frees up staff time to take on new cases.

Train staff

Plan to co-facilitate a family psychoeducation training before program implementation. This training would include didactic and experiential information about the techniques for best practice in single or multi-family processes. If needed, it would include didactic and experiential information about the techniques for best practice in culturally diverse settings.

Ensure ongoing supervision for facilitators

This is critical for the programs success. Supervision can be accomplished in person, or long distance through conference calls, telecommunication, or review of videos of the groups in process. Culturally knowledgeable supervisors or consultants are available for the major populations in the United States.

Provide important operational supports

Manage the details of implementation, such as locating a group meeting site, finding funding for refreshments, investigating reimbursement issues, defining documentation and quality improvement criteria, or facilitating a review of the agency's policies and procedures to be sure that they support FPE.

Track outcomes

Outcomes such as decreased relapse rates, decreased medication dosages, reduced family stress, and improved consumer employment and social skills should be tracked for all participants to gauge improvements. The same is true for tracking outcomes for culturally diverse groups, to ensure equity and maximum community benefit.

Maintaining and extending the gains of the family psychoeducation program

- To ensure that the organization will permanently adopt the family psychoeducation program and that staff will support it as a routine treatment modality, consider the following activities:
- Visibly recognize staff members who have made family psychoeducation a success in your program.
- Be prepared to train new staff, including clinical supervisors. This means continuously advocating for funding and changes in staffing patterns.
- Incorporate family engagement and education into the intake process, making it a clinical policy and routine procedure.
- Meet with family and consumer advocacy and education organizations to gather their experiences, assessments, and suggestions for improving the program and their role in helping support it.
- Provide family psychoeducation for all individuals and their families experiencing a first episode of a severe mental illness, especially psychosis.
- Find ways to gather and tell family psychoeducation success stories. Devote portions of staff meetings to sharing good news. This could include feedback and anecdotes from consumers, families, and employers.
- Meet with staff and administrators to address problems when they arise whether administrative or clinical in nature.
- Sponsor banquets to celebrate family psychoeducation achievements. Make a big deal out of the achievements and invite physicians and administrators to come to the celebration. Even consider inviting the director of the state's behavioral health division or the governor.
- Use relevant outcome statistics to justify the program's benefits and processes for continuously improving its effectiveness. This will clearly reinforce the consumer-centered outcome goal of the family psychoeducation program.

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Appendix: Co-facilitator job description

- Minimum college degree, with some clinical experience.
- Master's level degree is preferred.
- Interest in learning a non-process group intervention model that includes families.
- Interest in working with families and with individuals with serious mental illness.
- Background experience in family therapy is preferred.
- Willingness to adopt a new conceptual framework and practice paradigm.

IMPLEMENTATION TIPS FOR PUBLIC MENTAL HEALTH AUTHORITIES

The Evidenced-Based Practices Project presents public mental health authorities with a unique opportunity to improve clinical services for adults with severe mental illness. Service system research has evolved to a point where it can identify a cluster of practices that demonstrate a consistent, positive impact on the lives of people who have experienced psychiatric symptoms. These practices include integrated dual disorders treatment, supported employment, illness management and recovery, assertive community treatment, medication management and approaches to psychiatry, and family psychoeducation. This document focuses on family psychoeducation.

What is Family Psychoeducation?

Family psychoeducation is a specific method of working in partnership with consumers and families in a long-term treatment model to help them develop increasingly sophisticated coping skills for handling problems posed by mental illness. The goal is that practitioner, consumer, and family work together to support recovery. It almost always engenders hope in place of desperation and demoralization. There is abundant evidence for its effectiveness in working with consumers who experience schizophrenic disorders, but there is increasing research support, as well, for its use with mood disorders, OCD, borderline personality disorders, and even for consumers who lack family support altogether. Thus, those families and consumers with the most severe psychiatric disorders will experience the greatest benefit from FPE.

What is an Implementation Resource Kit?

Extensive research demonstrates that implementing family psychoeducation in routine mental health settings dramatically improves the lives of people with severe mental illness. To this end, a implementation resource kit has been designed to involve family members, consumers, mental health program leaders, and practitioners along with public mental health authorities in a consolidated effort to implement family psychoeducation into routine mental health settings. The goal is to support the recovery process of consumers by reducing symptoms, rehospitalizations, isolation, and unemployment.

Implementation resource kits include: a practitioners workbook, a review of the scientific evidence for superior outcomes, web-based resources, separate information sheets for families, consumers and practitioners, introductory and skills training videotapes, suggestions for mental health program leaders and administrators, financing recommendations, and information about outcome measures and fidelity scales.

What is the role of the public mental health authority in implementing evidence-based practices?

One of the primary and essential roles of the public mental health authority (PMHA) is to serve as leader in bringing all the stakeholders together (consensus building) to firmly understand and articulate a vision of family psychoeducation and a plan for the implementation of family psychoeducation across a mental health system. This can be accomplished by using evidence to demonstrate that the quality of care improves with the implementation of this practice without significantly increasing costs. The public mental health authority plays a pivotal role in assuring buy-in from the stakeholder groups.

In summary, effective PMHAs

- Articulate a vision
- Bring stakeholders together (consensus building)
- Plan the implementation process
- Demonstrate cost-effectiveness

A key element is the PMHA's relationship with the implementing mental health agencies. Experience and some research suggests that the state's PMHA, mental health centers, and hospitals need to agree and commit to implementing new practices. This is may be a new role for these groups and different relationships may need to be formed. The best outcomes occur when:

- commissioners and mental health trade associations act in concert with clear definition of roles and responsibilities;
- the local agencies and/or their trade association take a clinical and programmatic lead;
- the PMHA encourages the initiative and provides key forms of support, including, financial, publicity and other incentives for agencies.

In some states, it is worth noting that present reimbursement systems reward state and federal budgets when Evidence Based Practices are provided, but the additional implementation costs are borne by the local providers. Directives that local providers implement EBPs without additional support or profit-sharing arrangements have tended to increase friction between the state and local levels and have not easily led to success in implementing Evidence Based Practices. Thus, PMHAs should work to assess cost savings to the mental health system and find ways to support provider agencies regarding implementation costs and financial incentives for using Evidence Based Practices such as FPE.

There are a variety of roles the PMHA can play

- disseminating information about family psychoeducation
- promoting the implementation of family psychoeducation
- working in, and developing, partnerships with mental health centers and trade
- associations, a key to success in adopting and implementing this approach
- providing financial and political support, including fiscal and
- programmatic incentives
- exploring profit-sharing to provide equity and incentives for implementing FPE services

Planning for the change

Beyond consensus building, the PMHAs role is planning for, and leading, the change so that the practice will be accepted and sustained. This planning may include such factors as financing incentives, rules changes, contracting processes, human resources development, and assessment of outcomes. Just as important is the consistent communication of the expectation that services will meet current best-practice standards and, thereby, realize the potential benefits for all stakeholders. Presentations and orientation sessions by national EBP clinical leaders have proven essential and quite cost-effective in educating and persuading key stakeholders to commit to implementation.

The challenge of how to sustain the practice needs to be addressed as part of the initial planning process. The PMHA has to develop strategies to address this issue and ensure that it gets attended to so the practice will continue to grow and develop. Finally, the PMHA

will need to ensure that there is a system in place to collect data on the outcomes of the practice. This will help to identify systemic problems and help sustain the program.

What roles do families have?

PMHAs are generally aware that families can help create an optimal home and social environment for the individual with mental illness. Families should participate in decision-making about their loved ones future life and living situation. Families are playing new roles in public mental health and are willing to work with mental health authorities. For family psychoeducation to be successful and sustained, it is important that the mental health authority include families as an important stakeholder group in planning the implementation of a family psychoeducation program.

How can family psychoeducation be funded?

Funding mechanisms may vary from agency to agency and state to state. For the most part, funds are used from the state Division of Mental Health and Medicaid. State leaders from the agencies work out a mechanism on how to pool monies that can be used to reimburse the services of family psychoeducation programs. In some cases Medicaid rules and codes have been rewritten to allow reimbursement for family psychoeducation. One state has adopted a case-rate approach, which fits well with implementation and promotes use of the modality (details available on request). In some states, Medicaid authorities support funding for family psychoeducation because there is such a large reduction in emergency room visits and hospital admission costs.

Who supports family psychoeducation?

There are several sources of support to help implement and sustain family psychoeducation. For example, constituency groups that can serve as allies to help change the system include:

- Family advocacy organizations such as The National Alliance on Mental Illness (state and local chapters) and state mental health associations have long recognized that education and support programs are beneficial for families coping with mental illness. Reports show that families who have participated in the family psychoeducation programs often become strong advocates. They may be more willing to financially support and advocate for the general operations of the community mental health service system. They may also get involved on planning committees, advisory boards or in political activities to support mental health programs and funding.
- The Agency for Health Care Policy and Research supported an extensive review of the scientific literature on the outcomes of family psychoeducation. The Patient Outcomes Research Team's (PORT) findings were that FPE greatly reduces relapse, rehospitalization, and improves community functioning. Subsequent studies and reviews have concluded the same. Recently, family psychoeducation in multifamily groups has been found to reduce negative symptoms (the control group's symptoms increased) and medical care use and medical illness among the participating relatives.
- The American Psychiatric Association practice guidelines recommend family psychoeducation as a first line or indicated treatment for schizophrenic and bipolar disorders. (For more information, see the clinical measures section of their website at www.psych.org.)

What are the benefits of Family Psychoeducation?

Evidence shows that for consumers whose families participate in family psychoeducation programs, relapse rates and re-hospitalizations decrease significantly within the first year after hospitalization when compared to consumers who only use medication with, or without psychotherapy. With a family psychoeducation program in place there is evidence of savings in all areas that traditionally accompany relapse, including hospital costs and the need for police interventions and crisis intervention. Employment rates for consumers usually double; in combination with supported employment, they can quadruple. Because it reduces medical care needs for both consumers and their family members, it can reduce overall health care costs. Successful outcomes improve stakeholder support for the mental health authority, helping to sustain the program.

Outcome results are critical for demonstrating to the effectiveness of the program to funding sources and for persuading more agencies to participate. It is also important to point out to the specific stakeholders what they may expect as benefits from practice of family psychoeducation and to determine, with the stakeholders, if these benefits are supported by outcomes in local practice. These benefits have occurred across many cultural and racial groups, throughout the United States and in several international studies and programs. For example,

For consumers

- Helps build a support network for recovery
- Provides hope
- Reduces relapse and hospitalization
- Improves symptom management
- Reduces medication dosages
- Improves social skills and community participation
- Increases employment, earnings and career options
- Strengthens family ties
- Reduces family conflicts

For families

- Provides hope
- Provides skills to support recovery
- Improves understanding of the illness
- Improves coping skills
- Reduces medical illness and medical care utilization
- Reduces feelings of stigma and isolation
- Reduces stress
- Improves family relationships

For practitioners

- Improves consumer outcomes, community functioning, and satisfaction for consumers
- Enhances understanding of severe mental illness and how to treat it
- Helps to achieve higher rates of recovery for consumers
- Reduces the need for crisis intervention over time
- Improves relationships with families and consumers

For mental health agencies

- Savings in emergency room and hospitalization costs
- Reduces need for crisis intervention and agency disruption

- Improves staff morale and commitment to this population
- Multifamily groups serve general case management and other purposes
- Enhanced reputation and fewer complaints and conflicts with advocates
- Improves cost-benefit ratio
- Builds a network of allies for community mental health, especially with family advocacy groups

What are the costs of not using the FPE?

The excess cost associated with not using FPE may include:

- the continuation of a high relapse rate;
- unnecessary hospitalizations;
- frequent crises that must be managed by outpatient, emergency or crisis
- program staff;
- unnecessary deterioration of functioning;
- higher rates of unemployment for consumers;
- alienation and sometimes political action by families and family advocacy groups.

By contrast, in a statewide study in New York, during the second year of treatment, found that for every $1 in costs for FPE in multifamily groups, there was a $34 savings in hospital costs. In a typical hospital in Maine, there was an average net savings of $4,300 per patient, per year over two years. The minimum reduction in hospitalizations has been about 50%, with some studies achieving up to 75% reductions over time. Ratios of $1 spent for this service to $10 in saved hospitalization costs can be routinely achieved.

Will FPE work in this mental health system and with many different cultures?

FPE was specifically designed for use in publicly funded community mental health services. For instance, the multifamily group version of FPE was developed in the South Bronx under adverse circumstances in a multicultural context. It has been refined to be cost-effective in routine mental health settings in many types of communities. Similar results have been reported in the Watts section of Los Angeles, Pittsburgh, six different cities in New York State, a wealthy suburban county in New Jersey, throughout the state of Illinois and the entire state of Maine, in Spokane, Washington, and in the borough of Harlem in New York City. Services are being provided successfully in nine cities in Scandinavia, to the Asian immigrant community in Melbourne, Australia, to thousands of families in China and in Hungary. It seems unlikely that there is any particular clinical or population group for whom this approach cannot be provided with the same kinds of results, except where there are large numbers of people who have no family or friends who are able to participate (e.g., some parts of Manhattan).

Does FPE require new resources or can resources be reallocated?

In mental health systems in which some psychosocial or psychotherapy services are provided, family psychoeducation can be provided largely by reallocation of services. If multifamily groups are established, total service effort will actually decrease in absolute terms. In systems in which the only service provided is brief medication visits on an infrequent basis, new service effort will have to be provided. However, a recent cost-effectiveness study shows that the extra effort will be more than recouped in saved intensive treatment costs, leading to no net increase in staff time or effort. Some special arrangements may be needed to provide access to families from some cultural groups. For

some families, the program may need to use the services of a tele-interpreter service or its counterparts.

With respect to staffing, this approach is designed to largely replace individual meetings with consumers. Usually additional staffing will not be required until the program involves a very high proportion of the agency's consumers who are appropriate for the intervention. Most licensed mental health practitioners can learn to work within this model quite effectively. That includes social workers, psychiatric nurses, psychiatrists, psychologists, occupational therapists, and case managers.

What do consumers and families think of FPE?

The best answer lies in participation rates. In a major research demonstration project in six cities in New York State, providing services in both single- and multifamily formats, the drop out rate amongst very ill consumers from state and city hospitals was about 25% after two years. Most of the multi-family groups kept meeting for years afterwards. The major political problem faced by that project was that after several months of providing services, there were often complaints from families and consumers that more families were not being offered this service. Many mental health agencies that have offered these services for a period of time find that practitioners, consumers and families do not want them to end. However, the common challenge is finding the ongoing support very useful in improving the consumers functioning and community participation.

How can FPE be implemented successfully?

Creating a positive environment in a mental health system for the implementation of FPE by mental health agencies is a critical role of the PMHA. Family psychoeducation usually takes place in community mental health centers. Frequently, the work begins while the individual consumer is hospitalized and continues after discharge to outpatient services. People from a variety of disciplines have proven to be very effective practitioners of family psychoeducation, including social workers, psychiatrists, case managers, nurses, occupational therapists and even some expert family members.

How can the PMHA assure that agencies will faithfully adhere to FPE principles?

The implementation resource kit includes a fidelity measure that assesses how closely the program implementation follows the approaches that have achieved results in the studies cited in the review. This checks both the agency's and the practitioner's adherence to standards. How successful a program using an Evidence Based Practice, such as FPE, is in improving outcomes depends, in part, on how closely the program follows the EBP model. Programs that only partially adopt the model or that are allowed to drift back into old ways of providing care may not produce the beneficial outcomes associated with FPE. This will be especially true if agencies and their practitioners view and interact with the family in ways that imply that the family is at fault.

What are the costs?

For the services

The direct financial costs of providing FPE is about $350 per year, per consumer in staff time for an ongoing multifamily group when using a masters level practitioner (based on East Coast salary levels). The ongoing multifamily group sessions require about one hour of staff effort per month per consumer, after the initial engagement and education sessions.

Start-up costs are higher due to learning time and effort, initial single family sessions and the educational workshop. Each subsequent multifamily group requires less effort, as the learning curve flattens. Single-family format is roughly twice the cost per consumer.

To introduce the program

The initial implementation costs are about $250 per practitioner for staff recruitment, preparation, and associated costs for training.
Other agency costs include agency administration time, and staff time while participating in skills training, supervision and consultation activities.

What do people say about FPE?

The (consumer) is much better, more active, more aware of his illness and [he exerts] more control over recognizing prodromal symptoms and getting help early on. - L.B., FPE practitioner

The experience of this group has shown us again and again the truth of the old cliche, that we are not alone. - John and Susan, parents of a daughter who has mental illness

The rewards of implementing these groups include watching the families become stronger, more skilled, lighter; watching people with schizophrenia improve in functioning. -An Acadia Hospital administrator

Sample Medicaid Reimbursement Regulations and Code:

Proposed Descriptors of Family Psychoeducation The following language has been used to establish a special case-rate reimbursement methodology in the State of Maine.

Eligible Recipients

Those Medicaid recipients who are eligible to receive family psychoeducation include general and specific requirements as defined and elaborated in Sections 17.02-1,2 and 3. Persons meeting all other requirements but who are under the age of 18 will also be included as eligible.

Staffing

The practitioners eligible to provide family psychoeducation under Medicaid reimbursement include mental health professionals as defined in Chapter II, Section 17.09-1 and designated community support providers as defined in 17.09-2.

Covered services

Covered services include family psychoeducation provided in multifamily groups and in single family sessions. Covered services include family psychoeducation as defined under program elements provided to caretaking relatives and/or non-related caretaking persons, as well as to the eligible person. Covered services may be provided to the participating persons with or without the eligible person being present, if all other program requirements and elements are being provided.

Program elements of the covered services include:

Engagement sessions, usually involving caretakers and eligible Medicaid recipients, who may meet separately or together, depending on clinical condition and other considerations, to be determined by the eligible provider.

These sessions focus on:

- exploring precipitants of previous acute episodes of illness
- review of prodromal signs and symptoms
- reactions of the family in supporting family members with an illness
- coping strategies and strengths that have been successful
- social supports in the communities
- grief and mourning in relation to the illness and a contract for treatment and the development of a treatment plan

There may be three or more engagement sessions, as early in the course of an episode or illness as possible.

Educational workshops, involving caretaking relatives and, at the determination of the practitioners leading the workshop, eligible Medicaid recipients.

These workshops offer extensive information about the biological, psychological, and social aspects of mental illness, the nature, effects and side effects of psychiatric treatments, what families can do to facilitate recovery and prevention of relapse and guidelines for management of mental illnesses.

Ongoing supportive and problem solving sessions occur in a multifamily or single family format, usually with the eligible Medicaid recipient present.

These sessions follow an empirically tested format and focus on solving problems that interfere with treatment, illness and symptom management, and coping skills. Case management may also be accomplished during these sessions. They are usually biweekly, and become monthly after stability has been achieved. They continue for at least one year and two years is indicated for consumers who experience schizophrenic disorders.

FIDELITY SCALE: INTRODUCTION

Overview of FPE

FPE is an evidence-based psychiatric rehabilitation practice that aims to achieve the best possible outcome for consumers with severe mental illness (SMI) through collaborative treatment between clinicians and family members of the individual with SMI. Additionally, FPE attempts to alleviate the stress experienced by family members by supporting them in their efforts to aid the recovery of their loved one. Research has demonstrated that FPE results in a 20% - 50% reduction in relapse and rehospitalization rates among consumers whose families received psychoeducation than among those receiving standard individual services (Lam, Knipers & Leff, 1993; Penn & Kim, 1996; Falloon, Held et al., 1999). Moreover, families that receive education and support feel less burden and are more effective at helping their loved ones with SMI to manage their illnesses (Dixon & Lehman, 1995).

Although the existing models of family interventions vary, leaders in the field have reached a consensus on the critical ingredients of effective FPE. They include a collaborative relationship between the treatment team and family, basic psychoeducation about psychiatric illness and its management, social support and empathy, interventions targeted to reducing tension and stress in the family as well as improving functioning in all family members (and not just the consumer), and a program length of six months or more (Dixon, McFarlane et al., 2001).

What is meant by family?

The term family is used throughout this document. It should be interpreted broadly to including anyone in the clients natural support system who is functioning as family, regardless of any legal or biological relationship to the client. A family member could include not only parents, siblings, spouses, children, and other relatives, but also friends.

Overview of the scale

The 12-item FPE Fidelity Scale has been developed to measure the adequacy of implementation of FPE programs. Each item on the scale is rated on a 5-point rating scale ranging from 1 (Not implemented) to 5 (Fully implemented). The standards used for establishing the anchors for the fully-implemented ratings were determined through a variety of expert sources as well as empirical research.

What is rated

The scale is rated on current behavior and activities, not planned or intended behavior. For example, in order to get the full credit for Item 1 (Family Intervention Coordinator), it is not enough that the program is currently planning to hire personnel to fill the position.

Unit of analysis

The scale is appropriate for organizations that are serving clients with SMI and their families. The purpose of the scale is to assess fidelity to evidence-based practices at the program level, rather than at the level of a specific clinician.

How the rating is done

To be valid, we believe that a fidelity assessment must be done in person, i.e., through a site visit. The fidelity assessment requires a minimum of 5 hours to complete, although a longer period of assessment will offer more opportunity to collect information and hence should result in a more valid assessment. The data collection procedures include chart review, session observation, and semi-structured interviews with the program coordinator, clinicians and supervisors, and family members.
If the FPE program has 3 or fewer clinicians, attempts should be made to interview all. If the program has more than 3 clinicians, a minimum of 3 should be sampled for an interview. It is recommended that interviews with clinicians be done in a group format.

For the items that require interviews with family members, we suggest that at least 3 family members (from unique families) be interviewed. The program coordinator should be contacted to help you identify and set up these interviews.

For some items that require chart review for rating, 10 charts shall be randomly selected. We suggest that you ask the program coordinator to select 20 charts beforehand and then randomly select and review 10 of those charts during your site visit. The charts should include one client whose family is seen for each FPE clinician to be interviewed.
Some items are to be rated by observing a session. The rating may be done either by observing a live session or by viewing a previously videotaped session, which should be determined by negotiating with each program.

Who does the ratings

The scale can be administered internally by a program or by an external review group. If it is administered internally, it is obviously important for the ratings be made objectively, based on hard evidence, rather than making ratings to look good. Circumstances will dictate decisions in this area, but we encourage agencies to choose a review process that fosters objectivity in ratings, e.g., by involving a staff person who is not centrally involved in providing the service. With regard to external reviews, there is a distinct advantage in using assessors who are familiar with the program, but at the same time are independent. The goal in this process is the selection of objective and competent assessors.

Fidelity assessments should be administered by individuals who have experience and training in interviewing and data collection procedures (including chart reviews). In addition, interviewers need to have an understanding of the nature and critical ingredients of FPE. We recommend that all fidelity assessments be conducted by at least two assessors.

Missing data

The scale is designed to be completely filled out, with no missing data on any items. Therefore, it is essential that assessors obtain the required information for every item. If information cannot be obtained at time of the site visit, it will be important for you to be able to collect at a later date.

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FIDELITY SCALE PROTOCOL: ITEM DEFINITIONS AND SCORING

Many of the items on this scale call for a calculation of % of families for which a particular element of FPE is documented on standardized charts. This methodology implies that documentation is critical to evidence-based practice. While documentation is an important ingredient, poor documentation for an item does not mean that there is a complete lack of fidelity, nor does excellent documentation guarantee high fidelity of implementation. Fidelity assessors should integrate their observations from multiple sources to reach a reasoned judgment about the ratings for each item. To achieve a 5 (full implementation), all data sources (program coordinator, clinicians, family members, and charts) should agree that the item is fully implemented. If most, but not all, of the clinicians understand and follow the principle or intervention measured by an item, then ordinarily that item would be rated 4. If the organization cannot produce any written documentation whatsoever for implementation of an item, the item ordinarily should not be scored higher than 3. Rate 3 if the documentation is missing, but some clinicians can explain the principle and can give specific examples during the interview. Rate 1 if the documentation is missing and clinicians cannot articulate the underlying principles.

1. Family Intervention Coordinator
2. Session Frequency for Family Psychoeducation
3. Long-Term FPE
4. Quality of Clinician-Family Alliance
5. Detailed Family Reactions
6. Precipitating Factors
7. Prodromal Signs
8. Coping Strategies
9. Educational Curriculum
10. Multimedia Education
11. Structured Group Sessions
12. Structured Problem-Solving Techniques

1. Family Intervention Coordinator

Definition

One clinical administrator is designated as overseer of the family psychoeducation program for a substantial portion of his/her job (time depends on size of program). This persons role includes activities such as:

- Establishing, monitoring, and automating family intake and engagement procedures

- Advocating cases to staff
- Monitoring caseloads
- Arranging for staff training
- Training and preparing new staff
- Arranging supervision for staff

Rationale

Delivery of services to families must be subject to accountability and tracking. One effective way for mental health centers to monitor the delivery of family services is to create a position of Family Intervention Coordinator, who would also serve as the contact person for interventions, facilitate communication between staff and families, and supervise clinicians.

Sources of Information

The first obvious question is whether the organization has someone who has a title or family coordinator or equivalent. This should be determined prior to the site visit. During the fidelity visit, interview program coordinator, clinicians, and family members.

Item Response Coding

Program coordinator is the primary source of information for this item. If other sources do not report these responsibilities performed the coordinator, then fidelity assessors should follow up with program coordinator with clarifying questions and documentation (at end of the fidelity visit day or in follow-up call). If the program does not have a designated position of coordinator (or equivalent), the item would be coded as 1. If the program has a designated position of coordinator who performs all 6 tasks, the item would be coded as a 5.

Probe Questions

For program coordinator
What is your role in the FPE program? How much time do you devote to this? What kinds of responsibilities do you have? (Check which of the 6 tasks are performed by coordinator. Probe who performs tasks that were not mentioned, e.g., What are your programs family intake and engagement procedures? Who monitors caseload? Who trains your staff? How is the training done?)

Ask program coordinator to explain intake procedures, monitoring, training schedule, and supervision schedule.

For clinicians
What functions does the program coordinator perform? Does anyone have responsibility for each of the following?

For family members
What functions does the program coordinator perform?

2. Session Frequency for Family Psychoeducation

Definition
Families participate in at least biweekly FPE sessions.

Rationale

It is presumed that families are more successful in benefiting if sessions are offered on a regular, predictable basis.

Sources of Information

Chart review, roster of sessions, and interviews with program coordinator, clinicians, and family members.

Item Response Coding

The primary evidence for coding this item would be attendance rosters or a calendar of scheduled events, if such documents exist. The program should have some way of documenting frequency of FPE sessions. If the documentation suggests that the organization provides at least biweekly FPE sessions, the item would be coded as a 5.

Probe Questions:

For program coordinator and clinicians
How often are FPE sessions held for family members? Do you have attendance rosters, calendar of events, or other documentation to verify this?

For family members
How often are FPE sessions held for family members?

3. Long-Term FPE

Definition

Families are provided with long-term FPE; specifically, at least one family member participates in FPE sessions for at least 9-months.

Rationale

In general, 6-9 months of biweekly equivalent FPE sessions are required for the families to learn necessary information and problem-solving skills. Following completion of the program, the families may also benefit from booster sessions or support groups.

Sources of Information

Chart review, roster of sessions, and interviews with program coordinator, clinicians, and family members.

Item Response Coding

The primary evidence for coding this item would be a report containing the number of families completing FPE and how long they attended, records of duration of FPE groups, or attendance sheets. In the absence of written records, the assessment will depend on interviews. Excluding dropouts, if there is evidence that = 90% of families receive at least 9 months of FPE sessions, the item would be coded as a 5.

Probe Questions

For program coordinator and clinicians
How long do family members attend FPE before they graduate? Do you have a list of the Do you have attendance rosters, calendar of events, or other documentation to verify this?

For family members
How long attended FPE? How long do you intend to attend?

4. Quality of Clinician-Family Alliance

Definition

In individual or group sessions (approximately three sessions), the clinician engages family members and consumer with warmth, empathy, acceptance, and attention to each individuals needs and desires.

Rationale

When the alliance between clinician and family members is poor, family members are less likely participate fully or at all in FPE programs and, as a result, are less likely to benefit from FPE interventions.

Sources of Information

Interviews with clinician and family members, session observation.

Item Response Coding

The primary source for rating this item is direct observation. This item requires clinical judgment and is based on the fidelity assessors experience. Negative indicators would include comments in interviews, FPE sessions, or charts expressing judgmental or blaming attitudes. If sources consistently indicate a strong clinician-family alliance for all FPE clinicians, the item would be coded as a 5.

Probe Questions

For clinicians
How do you establish rapport or develop an alliance with family members? How would you rate or describe your alliance with Family X (select one family with whom the clinician works) in general? Are there any family members with whom you feel your relationship is counterproductive or poor?

For family members
How would you describe your relationship with Clinician X? Do you feel that he/she has worked to establish a good relationship with you? What has he/she done to connect with you? What has he/she done that makes it more difficult for you to work with him/her? What would you change about your working relationship with Clinician X to make it better?

5. Detailed Family Reactions

Definition

In individual or group sessions, the clinician(s) identify and specify the familys reaction to their relatives mental illness.

Rationale

A core principle of FPE is to help family members achieve a basic understanding of SMI as well as to resolve family conflict by listening and responding sensitively to each members emotional distress related to having a family member with an SMI.

Sources of Information

Chart review of treatment plan and interviews with coordinator, clinicians, and families.

Item Response Coding

The primary data source for this item is the treatment plans in the chart review. If documented for 80% or more of involved families, and these findings are corroborated by coordinator, supervisor, clinicians, and families, the item would be coded as a 5.

Probe Questions

For program coordinator and clinicians
In the FPE sessions, do you address how families react emotionally or behaviorally to their family members illness? What sorts of issues do you discuss? What sorts of activities do you engage in to help them deal with their reactions? Use a client chart for a family member seen by each clinician and ask the clinician to explain the specifics, including where in the chart this is documented.

For family members
Do you spend time in the sessions discussing how you feel and react in regards to the illness? Does the clinician lead you in activities to help you deal with your feelings/reactions?

6. Precipitating Factors

Definition

In individual or group sessions, the clinician(s) identify and specify precipitating factors to their relatives mental illness.

Rationale

Exploration of factors that have precipitated relapse in the past is a crucial step to developing individualized relapse prevention and illness management strategies. Involving the consumer and the family as equal partners in the planning and delivery of treatment is a core principle of FPE.

Sources of Information

Chart review and interviews with coordinator, clinicians, and families.

Item Response Coding

The primary data source for this item is a standardized checklist or progress note in the clients chart. If documented on standardized checklist for 80% or more of involved families, corroborated by coordinator, supervisor, clinicians, and families, the item would be coded as a 5.

Probe Questions

For program coordinator and clinicians
Do you discuss the precipitating factors of the illness with families? If yes. Can you describe the process you use to discuss them? Can you show me examples?
Use a client chart for a family member seen by each clinician and ask the clinician to explain the specifics, including where in the chart this is documented.

For family members
Do you discuss how to identify precipitating factors for the illness in the sessions? What sorts of things do you talk about? Please give examples.
Do you discuss ways in which you can respond once you notice these factors occurring? Are these strategies reviewed in later sessions?

7. Prodromal Signs

Definition

In individual or group sessions, the clinician(s) help families to identify and specify prodromal signs and symptoms of their relative's mental illness.

Rationale

Exploration of the consumer's prodromal signs is another crucial step to developing individualized relapse prevention and illness management strategies. Again, involvement of the consumer and the family as equal partners in the planning and delivery of treatment is a core principle of FPE.

Sources of Information

Chart review and interviews with coordinator, clinicians, and families.

Item Response Coding

The primary data source for this item is a standardized checklist or progress note in the clients chart. If documented on standardized checklist for 80% or more of involved families, corroborated by coordinator, supervisor, clinicians, and families, the item would be coded as a 5.

Probe Questions

For program coordinator and clinicians
Do you help identify prodromal symptoms for families? If yes. can you describe the process you use to help identify them? What would be specific examples? Use a client chart for a family member seen by each clinician and ask the clinician to explain the specifics, including where in the chart this is documented.

For family members
Do you discuss the signs that your family member may be becoming symptomatic? What sorts of things are suggested in your sessions for how to recognize the early symptoms of the mental illness? What would be specific examples? Are these suggestions reviewed in later sessions?

8. Coping Strategies

Definition

In single-family joining sessions, the clinician(s) help to identify, describe, clarify and teach coping strategies that are used by families.

Rationale

Exploration of coping strategies that have and have not worked is another crucial step to developing individualized relapse prevention and illness management strategies. Insight into patterns of ineffective interactions and behaviors is likely to motivate the family towards desired change.

Sources of Information

Chart review and interviews with coordinator, clinicians, and families.

Item Response Coding

The primary data source for this item is a standardized checklist or progress note in the clients chart. If documented on standardized checklist for 80% or more of involved families, corroborated by coordinator, supervisor, clinicians, and families, the item would be coded as a 5.

Probe Questions

For program coordinator and clinicians
Do you help identify coping strategies for families? If yes. can you describe the process you use to help identify and implement them? Use a client chart for a family member seen by each clinician and ask the clinician to explain the specifics, including where in the chart this is documented.

For family members
Do you discuss how to cope with your family member's illness in the sessions? What sorts of things do you talk about? Do you discuss other possible ways of coping or responding? Are these strategies reviewed in later sessions?

9. Educational Curriculum

Definition

In individual or group sessions, the clinician(s) use a standardized curriculum to teach families about mental illness. The curriculum covers six topics:

- Psychobiology of mental illness
- Diagnosis and treatment
- Family reaction and its stages
- Psychosis as a family trauma
- Relapse prevention
- Family guidelines

Rationale

An educational curriculum specifies what is taught and how it is taught. To effectively teach the families new information and skills requires structure and systematic use of specific evidence-based techniques and strategies. It is therefore critical that an FPE program has a written curriculum for its clinicians to follow.

Sources of Information

Coordinator and clinician interviews and curriculum review.

Item Response Coding

The primary data sources for this rating are a written curriculum accompanied by a schedule of completed sessions, corroborated with interviews. If = 90% of educational workshops (or single family sessions) cover all 6 areas, the item would be coded as a 5.

Probe Questions

For program coordinator
Does your program have a written curriculum for educational workshops? (If yes, request a copy for review.) How was it developed? How do you train your clinicians to use it? How do you ensure that your clinicians follow the curriculum? Do you periodically evaluate and update the curriculum? Do you have a schedule of completed sessions and their content? Ask about each of the listed areas above and whether they are included.

For clinicians
Do you use a written curriculum or clinicians manual for your educational workshops? (If yes) Are there any areas you teach differently from the curriculum/guide? Do you have a schedule of completed sessions and their content? Ask about each of the listed areas above and whether they are included.

For family members
What has been the content of the FPE sessions? Ask about each of the listed areas above.

10. Multimedia Education

Definition

Educational materials on illness, treatment, and guidelines can be provided in several formats (e.g., written, video, web sites).

Rationale

Depending upon the family, family members may benefit from receiving educational materials in a variety of formats. Some individuals may be more likely to watch a video or search a website than read the same information in a written format.

Sources of information

Interviews with coordinator, clinicians, and families.

Item Response Coding

The primary data source for this is the presentation of the actual materials and evidence that is made available to families. If documented on standardized checklist for 80% or more of involved families, corroborated by coordinator, supervisor, clinicians, and families, the item would be coded as a 5.

Probe Questions

For program coordinator and clinicians
In what form(s) do you provide educational materials to families? Do you always provide the information in the same format to each family? If not, how do you approach family members about what they need? How do you ensure that every family gets access to these materials? Ask to see the materials.

For family members
What types of educational materials have you been provided with? If they suggest a variety of materials, ask : Did you have to ask for materials in that format, or was it offered by the clinicians or program coordinator? If they suggest only written materials have been provided, ask: Have you ever been offered or provided with videos, website addresses or material in other formats?

11. Structured Group Sessions

Definition

FPE sessions follow a structured format consisting of:

- Socialization
- Go-round (i.e., turn-taking)
- Response to each family member
- Problem-solving component
- Socialization

Rationale

Families benefit most from structured sessions that follow a predictable pattern. Clinicians must also establish a clear agenda, goals and expectations for each session.

Sources of information

Observation of sessions and interviews with coordinator, clinicians, and families.

Item Response Coding

Primary data for this item is observation of a FPE session. If documented on standardized checklist for 80% or more of involved families, corroborated by coordinator, supervisor, clinicians, and families, the item would be coded as a 5.

Probe Questions

For program coordinator and clinicians
Can you describe the typical FPE multi-family group session? What activities do you engage in? Do you have specific goals for each of the FPE sessions?

For family members
Can you describe what you do at the beginning of each session? In the middle? At the end? Does session leader seem to have a structured approach to each session? Is it clear to you what will be accomplished in each session?

12. Structured Problem-Solving Techniques

Definition

In individual or group sessions, the clinician(s) use a standardized approach to help families with problem solving. The approach includes:

- Select a problem for one consumer/family
- Define the problem in behavioral terms
- Generate at least 8 suggestions for solution to the problem
- Explore with the consumer and family pros and cons for each suggestion
- Have consumer and family select the best suggestion
- With consumer and family, develop a step-by-step plan

Rationale

Studies show collaborative and structured problem-solving techniques involving setting realistic goals and priorities and breaking goals into small behavioral steps are effective in improving consumers functioning and families coping.

Sources of Information

Observation of a random sampling of sessions and interviews with coordinator, clinicians, and families.

Item Response Coding

The primary data source for this item is interviews with clinicians. If documented on standardized checklist for 80% or more of involved families, corroborated by coordinator, supervisor, clinicians, and families, the item would be coded as a 5.

Probe Questions

For program coordinator and clinicians
Do you focus on problem solving? If yes, what is/are your strategy(ies) for addressing this issue? Do you use the same set of strategies for each family? Listen for the list of 6 components given above. If a component is omitted, probe for whether it is included.

For the family members
During FPE, do you discuss how to address problems that may arise? If yes, what sorts of activities do you do in the sessions to work on problems you may be having? Do you ever generate plans of action? Is it a step-by-step procedure? Can you describe the steps?

FIDELITY SCALE COVER SHEET

Date:_____ Assessor(s) _____

Program Name:_____

Agency Name:_____

Contact Person:_____

Phone:_____

E-mail:_____

Sources Used:
_____ Chart review

_____ Interview with program coordinator

_____ Review of program documentation

_____ Observation of a session

_____ Interview with family member(s)

_____ Interview with clinician(s) Interview with

_____ Interview with

Number of clinicians:_____

Number of families served in preceding year:_____

Date program was started:_____

FIDELITY SCALE: CHECKLIST

Family Psychoeducation Fidelity Scale Checklist for Observed Sessions for Items 11 & 12.

Program Name:_____ **Session ID:** _____

Rater:_____

Item 11. Structured Group Sessions			
1) Socialization	*Yes*	*No*	
2) Turn-taking	*Yes*	*No*	
3) Response to each family member	*Yes*	*No*	
4) Problem-solving component	*Yes*	*No*	
5) Socialization	*Yes*	*No*	Rating: _____

Item 12. Structured Problem-Solving Technique			
1) Select problem for one consumer	*Yes*	*No*	
2) Define the problem in behavioral terms	*Yes*	*No*	
3) Generate at least 8 suggestions for solution	*Yes*	*No*	
4) Explore pros and cons for each solution	*Yes*	*No*	
5) Consumer and family select specific solution(s)	*Yes*	*No*	
6) Clinician and family collaboratively develop step-by-step plans for trying out the solution(s)	*Yes*	*No*	Rating: _____

FIDELITY SCALE SCORE SHEET

Program: _____

Date of Visit: _____

Informants Name(s) and Positions: _____, _____

Number of Records Reviewed: _____Rater: _____

Family Psychoeducation Fidelity Scale	1	2	3	4	5
1. Family Intervention Coordinator. One clinical administrator is designated as overseer of the family psychoeducation program for a substantial portion of his/her job (time depends on size of program). This person's role should include activities such as setting up FPE services, removing barriers to implementation, overseeing training and supervision, including family members in planning and oversight activities, linking with NAMI.	Agency does not have a designated position	Agency has a designated position who performs 1 of the tasks	Agency has a designated position who performs 2 or 3 of the tasks	Agency has a designated position who performs 4 or 5 of the tasks	Agency has a designated position who performs all tasks
2. Session Frequency for Family Psychoeducation	< 3 months	Every 3 months	Every 2 months	Monthly	At least twice a month
3. Long-Term FPE	Most families receive at less than 6 months of FPE sessions	Most families receive between 6-7 months of FPE sessions	Most families receive between 7-8 months	Most families receive between 8-9 months of FPE sessions	Excluding dropouts, >90% families receive at least 9 months of FPE sessions
4. Quality of Practitioner-Family Alliance. In individual or group sessions (approximately three sessions), the practitioner engages family members and consumer with warmth, empathy, acceptance and attention to each individual's needs and desires.	Sources consistently indicate poor practitioner-family alliance (e.g., all members of family and consumer decline services or drop-out)	Sources indicate that practitioner-family-consumer alliance often poor.	Sources indicate alliance is inconsistent or barely adequate, or information is inconsistent	Sources indicate a fairly strong practitioner-family-consumer alliance.	Sources consistently indicate a strong practitioner-family-consumer alliance
5. Detailed Family Reaction. In single-family Joining sessions, the clinician(s) identify and specify the family's reaction to their relative's mental illness.	<33% of involved families	33% - 49% of involved families	50% - 64% of involved families	65%-79% of involved families	Documented on standardized checklist for 80% or more of involved families, corroborated by coordinator, supervisor, clinicians, and families.

Family Psychoeducation Fidelity Scale	1	2	3	4	5
6. Precipitating Factors. In single-family Joining sessions, the clinician(s) identify and specify precipitating factors to their relative's mental illness.	<33% of involved families	33% - 49% of involved families	50% - 64% of involved families	65%-79% of involved families	Documented on standardized checklist for 80% or more of involved families, corroborated by coordinator, supervisor, clinicians, and families.
7. Prodromal Signs. In single-family Joining sessions, the clinician(s) help families to identify and specify prodromal signs and symptoms of their relative's mental illness.	<33% of involved families	33% - 49% of involved families	50% - 64% of involved families	65%-79% of involved families	Documented on standardized checklist for 80% or more of involved families, corroborated by coordinator, supervisor, clinicians, and families.
8. Coping Strategies. In single-family Joining sessions, the clinician(s) help to identify, describe, clarify, and teach coping strategies that are used by families.	<33% of involved families	33% - 49% of involved families	50% - 64% of involved families	65%-79% of involved families	Documented on standardized checklist for 80% or more of involved families, corroborated by coordinator, supervisor, clinicians, and families.
9. Educational Curriculum. In individual or group sessions, the clinician(s) use a standardized curriculum to teach families about mental illness. The curriculum covers at least six topics: psychobiology, diagnosis, treatment and rehabilitation, reactions to experiencing psychosis as a family, relapse prevention, and family guidelines.	<33% of involved families	33% - 49% of involved families	50% - 64% of involved families	65%-79% of involved families	Documented on standardized checklist for 80% or more of involved families, corroborated by coordinator, supervisor, clinicians, and families.

Family Psychoeducation Fidelity Scale	1	2	3	4	5
10. Multimedia Education. Educational materials on illness, treatment, and guidelines are provided with choices in several formats (e.g., written, video, web sites).	<33% of involved families	33% - 49% of involved families	50% - 64% of involved families	65%-79% of involved families	Documented on standardized checklist for 80% or more of involved families, corroborated by coordinator, supervisor, clinicians, and families.
11. Structured Sessions. Multiple- or single-family sessions follow a structured procedure that includes socialization, go-round, response to each family, problem solving, and socialization.	<33% of involved families	33% - 49% of involved families	50% - 64% of involved families	65%-79% of involved families	Documented on standardized checklist for 80% or more of involved families, corroborated by coordinator, supervisor, clinicians, and families.
12. Structured Problem-Solving Techniques. In individual or group sessions, the clinician(s) use a standardized approach (identify the problem, define the problem for one patient/family, generate >7 solutions, review pros and cons, select a solution, develop specific and individualized tasks and plans) to help families with problem-solving.	<33% of involved families	33% - 49% of involved families	50% - 64% of involved families	65%-79% of involved families	Documented on standardized checklist for 80% or more of involved families, corroborated by coordinator, supervisor, clinicians, and families.

USING FIDELITY SCALES FOR EVIDENCE-BASED PRACTICES

What is fidelity?

Fidelity refers to the degree of implementation of an evidence-based practice (EBP). A fidelity scale measures fidelity. Such scales have been developed for each of the six EBPs included in the Implementing EBP Project (assertive community treatment, supported employment, integrated treatment for dual disorders, illness management, family psychoeducation, and medication guidelines). Each scale assesses approximately 15 to 30 critical ingredients of the EBP, based on its underlying principles and methods. The scale items provide concrete indications that the practice is being implemented as intended. For example, one item on the Supported Employment Fidelity Scale concerns rapid job search. This item is rated as fully implemented if the consumers in a program average one month or less between admission to the supported employment program and their first job interview.

Why measure fidelity?

Several assumptions underlie the use of fidelity scales. First, a fidelity scale should adequately sample the critical ingredients of the EBP to differentiate between programs that follow the practice and those that do not. Research suggests that fidelity scales for supported employment and for assertive community treatment do accomplish this. Second, fidelity scales should be sensitive enough to detect progress in the development of a program from the start-up phase to its mature development. There is some evidence that fidelity scales achieve this goal as well. Third, high-fidelity programs are expected to have greater effectiveness than low-fidelity programs in achieving desired consumer outcomes. Several studies comparing fidelity ratings to outcomes also support this assumption.

One key use of fidelity scales is for monitoring programs over the course of their development (and even after they are fully established). Experience by implementers suggests that routine use of fidelity scales provides an objective, structured way to give feedback about program development. This is an excellent method to diagnose program weaknesses and clarify strengths for providing positive feedback on program development. Fidelity scales also provide a comparative framework for evaluating statewide trends and outliers. The strategic use of repeated evaluations of programs using fidelity scales, either on an individual program or statewide level, is based on the general principle that whatever is paid attention to is more likely to be improved.

How are fidelity scales used?

In the Implementing EBP Project we have developed fidelity scales that are simple to understand. EBP items are rated on a 5-point response format, ranging from 1 equaling no implementationto 5 equaling full implementation, with intermediate numbers representing progressively greater degrees of implementation. The response alternatives are behaviorally anchored, identifying measurable elements of the practice. Independent evaluators using multiple sources of information make the most valid ratings. Sources of information include interviews with staff, observation of team meetings, review of charts, and intervention observations. A daylong site visit is the optimal method for acquiring this information. Interviewers should be familiar with the EBP being rated. Although we recommend outside raters, fidelity scales can also be used by program managers to conduct self-ratings. The validity of self-ratings (or any ratings, for that matter) depends on the knowledge of the person making the ratings, access to accurate information pertaining to the ratings, and the objectivity

of the ratings. We encourage the use of self-ratings, with appropriate caveats regarding potential biases that could be introduced by raters invested in seeing a program look good or who do not fully understand the principles of the EBP. In addition to the scales developed for independent evaluators and program managers, companion fidelity measures intended for consumers and family members are under development for some EBPs.

Graphing fidelity ratings

We recommend that programs implementing an EBP graph their fidelity ratings over time, using their total fidelity score. By graphing this score, a program can see its change over time. When the program shows greater fidelity over time, this serves to reinforce their efforts. Another feature of graphing fidelity is to examine the cut-off score for full implementation. A program can use this score as a target and measure accordingly.